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*Policy Evaluation of the Effects of the 1996
Welfare Reform Legislation on SSI Benefits
for Disabled Children: Second Round Case
Study Findings*

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DRU-2224-SSA

May 2000

Submitted to the Social Security Administration
Contract Number: 0600-96-27335
Order Number: 0440-97-31436
Task Manager: Paul S. Davies, Ph.D.
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Labor and Population Program

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PREFACE

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (Title II (Subtitle B) of PL 104-193) created a more restricted definition of disability used to determine eligibility for disabled children under the Supplemental Security Income (SSI) program. The law required a redetermination of eligibility for children receiving SSI who might not meet the new definition. Benefits would be discontinued for children who did not meet the new disability definition. In addition, the law required that all children reaching age 18 have their eligibility for SSI redetermined based on the adult disability criteria.

This report is part of an evaluation being conducted by RAND for the Social Security Administration (SSA) titled "Policy Evaluation of the Effect of the 1996 Welfare Reform Legislation on SSI Benefits for Disabled Children". The evaluation focuses on the effects of the 1996 welfare reform legislation on SSI caseloads and costs and on the well-being of children and their families. The policy evaluation includes analyses of SSA administrative data, nationally representative secondary databases, and interviews with affected families, SSA administrators, and local agency administrators in four states to provide illustrative descriptions of policy impact on families. This report focuses on qualitative assessments of policy impact based on these interviews. Additional information about the RAND evaluation can be found in:

Rogowski, Jeannette A., Lynn A. Karoly, Jacob A. Klerman, Robert Reville, Moira Inkelas, Jill Houbé, Melissa Rowe, Narayan Sastry, and Jennifer Hawes-Dawson, *Background and Study Design Report for Policy Evaluation of the Effect of the 1996 Welfare Reform Legislation on SSI Benefits for Disabled Children*, DRU-1808-SSA, Santa Monica, California: The RAND Corporation, April 1998.

This report summarizes the findings from the second round of interviews conducted in 1999, and complements the first round interviews conducted in 1998 which are documented in the following report:

Inkelas, Moira, Melissa Rowe, Lynn A. Karoly, and Jeannette A. Rogowski, *Policy Evaluation of the Effects of the 1996 Welfare Reform Legislation on SSI Benefits for Disabled Children: First Round Case Study Findings*, DRU-2017, Santa Monica, California: The RAND Corporation, June 1999.

Other documents produced to date as part of the evaluation are:

Karoly, Lynn A., Randall A. Hirscher, and Jeannette A. Rogowski, *A Descriptive Analysis of the SSI Childhood and Age-18 Disability Redetermination Process: Results Through February 26, 1999*, DRR-2299-SSA, Santa Monica, California: The RAND Corporation, forthcoming.

Karoly, Lynn A., Randall A. Hirscher, and Jeannette A. Rogowski, *A Descriptive Analysis of the SSI Childhood and Age-18 Disability Redetermination Process: Results Through May 30, 1998*, DRR-2144, Santa Monica, California: The RAND Corporation, forthcoming.

Reville, Robert, Moira Inkelas, Jeannette A. Rogowski, and Lynn A. Karoly, *Data Sources to Evaluate the Effect of the Welfare Reform Legislation on Disabled Children*, DRR-1815-SSA, Santa Monica, California: The RAND Corporation, February 1998.

This research is funded by contract number 0600-96-27335 from the Social Security Administration. The opinions expressed and conclusions drawn in this report are the responsibility of the authors, and do not represent the official views of the Social Security Administration, other Agencies, or RAND.

CONTENTS

PREFACE.....	iii
TABLES	ix
SUMMARY	xi
ACKNOWLEDGMENTS	xix
ACRONYMS	xxi
1. INTRODUCTION	1
1.1 Background of the SSI Childhood Disability Program	1
1.2 Overview of the 1996 Changes to Childhood SSI Eligibility and Related Policy Changes.....	3
1.3 Objectives and Approach of the Case Studies	6
2. CASE STUDY METHODOLOGY	9
2.1 Selection and Characteristics of Case Study States	9
2.2 Selection and Characteristics of Local Sites Within Case Study States	12
2.3 Interviewing Protocols for SSA and Other Agency Staff.....	13
2.4 Interviewing Protocols for Families	14
2.5 Strengths and Limitations of the Study Design	21
3. SITE VISIT SUMMARY: LOS ANGELES, CALIFORNIA	23
3.1 Introduction	23
3.2 Summaries of Interviews with SSA Offices.....	24
3.3 Summary of Interview with Medicaid Agency	36
3.4 Summaries of Interviews with Other Agencies.....	38

3.5 Summary of Family Interviews	40
4. SITE VISIT SUMMARY: FRESNO, CALIFORNIA.....	47
4.1 Introduction	47
4.2 Summaries of Interviews with SSA Offices.....	47
4.3 Summaries of Interviews with Other Agencies.....	55
4.4 Summary of Family Interviews	58
5. SITE VISIT SUMMARY: HARTFORD, CONNECTICUT	65
5.1 Introduction	65
5.2 Summaries of Interviews With SSA Offices.....	66
5.3 Summary of Interview with Medicaid Agency	78
5.4 Summaries of Interviews with Other Agencies.....	79
5.5 Summary of Family Interviews	83
6. SITE VISIT SUMMARY: NEW ORLEANS, LOUISIANA.....	89
6.1 Introduction	89
6.2 Summaries of Interviews with SSA Offices.....	90
6.3 Summary of Interview with Medicaid Agency	101
6.4 Summaries of Interviews with Other Agencies.....	103
6.5 Summary of Family Interviews	108
7. SITE VISIT SUMMARY: DETROIT, MICHIGAN.....	115
7.1 Introduction	115
7.2 Summaries of Interviews with SSA Offices.....	116
7.3 Summary of Interview with Medicaid Agency	127
7.4 Summaries of Interviews with Other Agencies.....	127
7.5 Summary of Family Interviews	131

8. SUMMARY OF FINDINGS ACROSS CASE STUDY SITES	137
8.1 Summary of Findings from Agency/Provider Interviews	137
8.2 Summary of Findings from Family Interviews.....	143
8.3 Issues for Future Study	157
8.4 Conclusions	160
APPENDIX: OVERVIEW AND CHRONOLOGY OF REDETERMINATION PROCESS	163
A.1 Redetermination Process Following PRWORA.....	163
A.2 Policy Changes Following the Balanced Budget Act of 1997 and the Commissioner's 1997 Top-to-Bottom Review.....	164
REFERENCES	167

TABLES

Table 2.1—Topics for Agency Case Study Interviews	14
Table 2.2—Totals in Interview Sample by Strata	17
Table 2.3—Loss to Follow-up for Interview Sample by Strata	18
Table 2.4—Topics for Family Case Study Interviews	19
Table 8.1—Summary of Family Characteristics and Range Across Sites in 1998	144
Table 8.2 —Summary of Family Impact and Range of Responses Across Sites	146
Table 8.3—Summary of Questions for Further Study.....	159

SUMMARY

The SSI (Supplemental Security Income) program is administered by the Social Security Agency (SSA) and provides monthly cash benefits to the parents of low-income children with qualifying disabilities. The SSI childhood disability program was enacted by Congress in 1972 and was implemented in 1974. A child met SSI criteria for disability if he or she had a physical or mental impairment that had lasted or was expected to last for twelve months or was terminal. A child's impairment had to be comparable in severity to an impairment that would prevent an adult from working. Children's participation in the SSI program had increased since the program's inception and expanded dramatically in the early 1990's. The Personal Responsibility and Work Opportunity Reconciliation Act (P.L. 104-193) (Title II (Subtitle B)), signed into law by President Clinton on August 22, 1996, provided a new, more restrictive statutory definition of disability for children applying for SSI. This law has caused a significant number of children to lose SSI benefits because they no longer meet eligibility criteria.

The Social Security Administration (SSA) funded RAND to conduct an objective policy evaluation to understand the impact of changes to the SSI childhood disability criteria resulting from the 1996 legislation. The policy evaluation funded by the SSA Office of Research, Evaluation, and Statistics, titled "Policy Evaluation of the Effect of the 1996 Welfare Reform Legislation on SSI Benefits for Disabled Children", includes analyses of SSA administrative data, analyses of nationally representative survey data and of Medicaid data, and qualitative interviews conducted in 1998 and 1999 in four states. This report presents the findings from the 1999 follow-up interviews conducted with affected families, SSA administrators, and local agency administrators. These interviews focus on the effects of the welfare reform law on child SSI recipients and on local support systems for children with disabilities. This report also integrates key findings from the 1998 interviews and complements the report on the first round of interviews documented in Inkelas et al. (1999).

These case studies provide qualitative information on the effects of the policy change, based on the perceptions and experiences as reported by families and agency administrators. The primary purpose of the case studies is to obtain local perspectives and illustrative descriptions of policy impact. The synthesis of family experiences and local agency perceptions describes a possible range of policy effects, as reported by a small number of affected families, and by agencies who serve children with disabilities. The findings also will be used to generate important questions about policy impact and to interpret findings from the quantitative analyses in the policy evaluation.

The detailed qualitative information adds to our understanding of welfare reform impact for child SSI recipients. However, the case studies undertaken within the policy evaluation do not permit generalization about policy effects for all families and communities. The outcomes do not necessarily reflect what would be observed for a larger and statistically representative sample of the affected agencies and populations in

the communities visited, or what would be observed for the country as a whole. The conclusions that are drawn based on the interview findings are not intended to be definitive statements about the overall experiences of families and providers in the sites we visited, or about the experiences of those in other communities. As other components of the evaluation are completed, the qualitative data can be integrated with the quantitative analyses to provide a more complete portrait of the impact of the policy changes.

To obtain qualitative assessments of policy impact based on a range of perceptions and experiences over time, two rounds of interviews were conducted in five locations across the nation. The locations included Los Angeles and Fresno, California; Detroit, Michigan; Hartford, Connecticut; and New Orleans, Louisiana. In the two rounds of site visits, we interviewed SSA staff; representatives of state/local agencies (such as Medicaid, mental health, and public health); legal advocates; and 44 families with children who were affected by the welfare reform changes to childhood SSI eligibility.

The first round of interviews was conducted between August and October 1998 and focused on the eligibility redetermination process, the initial impact of welfare reform changes to SSI on children and families, and the initial responses of families to redetermination and to the loss (or potential loss) of SSI income. This report focuses on the findings from follow-up interviews that were conducted one year later in 1999 with these families and many of the same agencies.

The major findings from the second round of interviews are delineated below. Findings from interviews with SSA offices and with other local agencies are presented first and are followed by findings from interviews with families of affected children. While some of the major findings from the first round of case studies in 1998 are cited in this report, the second round report focuses on more recent issues and trends and integrates findings on the overall impact of the welfare reform changes over the last two years.

Impact on SSA Offices

SSA offices were faced with overwhelming and complex workloads but by 1999 perceived some benefits of the process.

Agency respondents consistently reported in 1998 that the childhood SSI disability changes created overwhelming workloads for federal SSA offices as well as for the state disability determination agencies. The incremental adjustments during the policy's implementation and the monitoring procedures that developed over time created a highly complex set of policies and procedures. By 1999, the eligibility determination procedures for childhood cases had become more routine. Many staff reported that the eligibility determination process was more complex, individualized, and resource-intensive than it had been in the past. A number of staff identified lasting, positive effects of the policy change. These included: (1) experience and knowledge gained by disability examiners and Disability Hearing Officers; (2) enhanced roles of claims representatives in local SSA

offices with families; and (3) greater perceived fairness and completeness of the new eligibility determination criteria and procedures.

The dedicated accounts policy increased the childhood workload in SSA field offices.

Although separate from the SSI childhood disability eligibility changes, implementation of the dedicated accounts policy was reported in 1998 and 1999 as an emerging issue in the SSA field offices that we visited. This policy restricts the way that families can access and spend lump sum SSI payments received after successfully appealing a child's cessation of benefits. Dedicated accounts were established for some children whose cessations were overturned on appeal. These were reported by staff to be time-consuming because of the need for individual judgment and monitoring and the fact that these accounts create new roles for field office staff.

Some states reported new applications from children who lost SSI under the new disability determination and whose cases were closed.

Administrators in several SSA offices stated that new applications had been received for children who were receiving SSI in August 1996 but lost SSI following eligibility redetermination. Staff reported that when these applications were received, there was generally an attempt to determine whether the child's eligibility could be handled as an appeal or whether a new application would be necessary. If the application was handled as an appeal, then significant retroactive benefits would be involved if eligibility was affirmed after determination.

Impact on Medicaid and Other Agencies

Some Medicaid agencies experienced difficulties identifying eligibility status for children undergoing redetermination, and due to the extended appeals process have not yet evaluated their implementation of the "grandfathering" provision of the 1997 Balanced Budget Act.

Many children continued to be in the appeals process through 1999. Therefore, Medicaid agencies in the states we visited that link SSI to Medicaid eligibility had not all fully implemented the Balanced Budget Act of 1997 provisions for "grandfathering" Medicaid eligibility for some affected children. Our interviews with Medicaid agency staff in 1998 had revealed that as of mid-1998, it was not yet clear in these states exactly how pre-welfare reform SSI criteria information would be gathered for this "grandfathered" group, or what information the state might require in future eligibility determinations. Administrators from most of these states expected that children who lose eligibility for SSI-linked Medicaid would still qualify for Medicaid in a low-income or cash assistance aid category, or else would qualify for the new federal Title XXI State Child Health Insurance Program (SCHIP) in the state. Some administrators voiced concern that some children could become disenrolled from Medicaid if the family did not respond to notifications of potential changes in eligibility status. By 1999, a class action lawsuit had

been filed against one state Medicaid agency based on its handling of Medicaid eligibility for children affected by SSI changes.

The initial impact of the childhood eligibility change on agencies serving children with disabilities has been less than expected for most agency administrators.

In 1998, a number of interviewed agency administrators and providers stated that they had expected to have a more substantial role in responding to the policy changes. Some of the administrators of support programs for children with disabilities expected that they would observe a larger impact on their populations than they had observed so far. Legal assistance programs had undertaken significant planning efforts and had assembled resources in response to the eligibility changes. However, those we interviewed had not yet seen a large number of requests for assistance from families. These trends generally continued in 1999. A number of agency administrators noted that it was difficult to identify the specific impact of SSI eligibility changes for children with disabilities because of the significant impact of other welfare reform changes, including AFDC/TANF reforms. Also, children receiving SSI have not been identified or tracked as a specific group within the populations served by these agencies. Some administrators indicated that an impact on child programs may be seen in the future if families of the affected children reach a crisis stage.

Impact on Children and Families

Most parents understood the SSI changes in welfare reform but were confused by the redetermination procedures.

Most families that we interviewed stated that they understood most aspects of the redetermination including the following: initial SSA letters that described the 1996 welfare reform changes regarding SSI; the purpose of the redeterminations that were underway; and options for appeal. One feature of the process that families found confusing was how the appeals process worked. Families also expressed confusion about the implications of requesting benefit continuation during appeal and the possible payback requirements. Some families described aspects of the redetermination process where they had not followed through. These aspects included completing forms, submitting forms in a timely way, or attending a scheduled appeal hearing. Some had followed through after receiving encouragement from a family member or friend. Few families reported seeking legal assistance or having been denied legal assistance. Most recalled being notified of their option to obtain legal assistance, however. Several families who were reaching the final stages of the appeals process were considering legal assistance as an option.

Some children in every site became disenrolled or lost Medicaid eligibility during redetermination and/or during the appeals process.

At least one parent in each site that we visited reported that their child had lost Medicaid eligibility or had become disenrolled for some period during the SSI eligibility

redetermination or appeals process. Medicaid losses were reported by some of the interviewed families even in the states that had not yet undertaken Medicaid eligibility redeterminations for the affected children, and in states with generous Medicaid income eligibility criteria for children. Retention of Medicaid appeared to be a more significant problem for those children who reached age 18. By the second interview in 1999, half of the children in the interviewed families who had not had Medicaid restored were 18 years of age or older. Given complex Medicaid eligibility rules and the fact that significant income changes were occurring for many of the families we interviewed, the specific reason for Medicaid loss was not always possible to identify in the family interviews. Some of the families who reported that the child had lost Medicaid stated that they had not yet contacted the local welfare office to determine the reason. Several families specifically stated that they had not had much contact with the local welfare office when their child received SSI-linked Medicaid and that they did not want to become involved with the local office to pursue other Medicaid eligibility options.

Some families felt that the changes to the child's Medicaid eligibility and/or loss of the SSI income had impaired their ability to obtain needed services for their child. Most families who reported difficulties with access pointed to delivery system issues rather than income or health insurance issues.

In 1998, some families reported that they were required to switch the affected child from fee-for-service Medicaid to a prepaid health plan (PHP) arrangement or that they anticipated such a requirement. By 1999, no additional families reported such changes or reported concerns about the potential impact of a change. In several of the families, the parent(s) had enrolled their child in private employer-based health insurance after the child lost Medicaid eligibility and felt that this had restricted the child's access to health care services relative to the benefits that had been available to the child through Medicaid. Few families identified PHP participation by itself as posing access barriers for their child. Overall, access to mental health providers of choice and getting access to services in the school were the major concerns identified by parents. Specific access difficulties raised in 1998 and in 1999 included the following: the ability to find a psychiatrist who participated in Medicaid; finding a pediatrician or pediatric specialist who could meet the child's specific medical or mental health need; the ability to obtain preventive family support services or child welfare services without having to enter the foster care system; and the ability to get appropriate medications for a child given Medicaid formulary limitations. Several parents stated that their child was not receiving needed services because the parent could not find an appropriately trained provider.

Many families identified access to mental health or health services as more important than restoring lost SSI income.

The families we interviewed frequently stated that the child's access to medical and mental health services was more important to them than restoring or replacing SSI income. Several parents expressed specific needs for respite care, for solutions to behavior problems that required parents to visit the school during the workday, or for

tutoring assistance for their child's learning problem. Several parents reported feeling that they could only access a meaningful intensity of mental health services through crisis intervention or foster care. Many parents stated that their child's health status had improved since initially receiving SSI, and that the SSI loss had not affected the child's health status by 1999. As expected, the children in interviewed families had different types of mental and physical impairments. There was no common agency or program serving all of the children. Some were not receiving services other than personal medical care.

Total household income declined in most families who lost SSI income but increased for others.

Many of the parents we interviewed stated that the loss of SSI benefits caused them to enter the workforce or to increase their working hours. Most families had not been able to compensate fully for lost SSI income by increased work participation. Some families stated that they had temporarily increased their total household income by applying for Food Stamps at the same time that they requested SSI benefit continuation during an appeal. By 1999, total household income had increased for approximately 25 percent of the families we interviewed. The increase usually came from a combination of increased work hours and additional public assistance. A small number of parents reported in 1999 that household income had declined by more than the SSI benefit amount. These parents stated that they had quit a job or reduced their working hours to meet the increased demands of a child from behavior problems in school or from other health problems. Kin foster parents did not appear to be compensating for lost SSI income by accessing significant public income support through child welfare, such as federal Title IV-E foster care or other state funds for out-of-home placement.¹

Many families initially turned to public assistance to replace lost SSI income but were no longer receiving the same level of public assistance by 1999.

Of the 25 percent of families who had turned to public assistance by 1998 to compensate for losing SSI income, nearly all reported turning to welfare and Food Stamps programs. The number of families receiving public assistance other than SSI declined from 18 percent in 1998 to 11 percent in 1999. Most of these families stated that their public assistance had declined because they had entered the work force or because they had reached cash assistance time limits imposed by welfare reform. Several parents were trying to obtain child support payments from absent fathers because the child had lost SSI or because the family expected the child to lose SSI.

¹ Title IV-E is part of the Social Security Act and provides for federal payments with state share for low-income children in qualifying out-of-home placements due to abuse or neglect.

Several foster parents of children who lost SSI experienced difficulties in maintaining custody of the children.

Children who were in kin foster care arrangements when SSI eligibility changed appeared to be more vulnerable to living arrangement changes. Several of the foster caretakers (all grandparents) expressed concern in 1998 that the loss of SSI might make it difficult for them to continue caring for the children. Several kin foster parents we interviewed had given up custody of the child or anticipated having to return the child to the foster care system. By 1999, one of the six foster grandparents had given custody of the child to another relative due to the income loss. Some kin foster parents reported that they received small child welfare payments, but that assistance had not increased after SSI was lost. Others reported that they had substituted TANF benefits for SSI or stated that they were not receiving public income support for the children in their custody.

Summary of Findings

The qualitative findings show that many families were affected by the SSI changes as well as by changes to cash assistance eligibility following welfare reform. The children in families we interviewed were not found to be participants in any specific federal or state program such as developmental services programs or the Title V program². Interviews with Medicaid administrators and from families generally corresponded with respect to the policy impact on Medicaid eligibility and participation. For children under age 18, systematic losses of Medicaid eligibility were not expected by agency administrators. In the families we interviewed, those children under 18 who had lost Medicaid for any period of time had generally experienced an intermittent loss with coverage later restored. For the small number of children under 18 who remained unenrolled in Medicaid by 1999, changes in household income made it difficult to know whether the children were financially eligible or not. Children age 18 and above experienced eligibility problems. Those over age 18 were identified by Medicaid administrators as a group whose eligibility could be adversely affected by SSI loss. The majority of those over age 18 who lost Medicaid were uninsured at the 1998 and 1999 interviews. Few reported having impairments that were leading to unmet health needs given lack of health insurance.

Few families stated that the SSI loss had adversely affected the child's health status. A large number of families identified access to quality medical care or mental health care as a more significant problem. Families did not perceive these access problems as related to loss of SSI or even loss of Medicaid. Instead, parents voiced concerns about their inability to find a provider with training they considered appropriate for their child's needs. Both families and a number of agency administrators reported that supportive services in mental health and child welfare were lacking in their communities. Agency administrators often noted that children such as those affected by the new SSI disability definition may not be identified until those families who are unable to cope reach a crisis stage. Overall, our findings suggest that income support to kin caregivers and ways of directing families to pre-crisis support services were primary needs of families losing SSI income.

² Title V, Part 2, of the Social Security Act contains a provision for the appropriation and allocation of federal funds to states, to serve children with physically disabling medical conditions.

ACKNOWLEDGMENTS

We would like to thank Paul Davies, the SSA Task Manager, for useful comments during the process of planning for and implementing the first and second rounds of case studies. Other SSA staff including Kalman Rupp, the SSA Project Officer, Howard Iams, and Steve Sandell provided useful feedback during the design phase for the case studies reported here. Useful input during the design phase also was provided from members of SSA's Technical Support group: Charles Manski (Northwestern University), Walter Oi (University of Rochester), Josh Angrist (Massachusetts Institute of Technology), Marta Tienda (Princeton University), Robert Hauser (University of Wisconsin, Madison), Mary McKay (SSA), David Baugh (HCFA), Chuck Haven (SSA), Cindy Bascetta (GAO), Karen Sherif (SSA), Bill Marton (DHHS/ASPE), and Don Oellerich (DHHS/ASPE). Helpful comments from SSA staff on a draft of the first round case study report that also informed the second round report were provided by Paul Davies and Kalman Rupp, and by Paul O'Leary, Suzanne Payne, and Mary Barbour (from ORES), from Alan Shafer (from the Office of Disability), and from Jessie Allen and Bill Anderson (from the Office of Disability, Division of Medical and Vocational Policy).

In designing and conducting the case studies, we also benefited from the helpful advice of Garrett Moran from Westat and David Stapleton from the Lewin Group, and from insights offered in the Interim Report on the DA&A Evaluation (Stapleton et al., 1998). We also thank Kathy Lazear and Mario Hernandez from the Florida Mental Health Institute at the University of South Florida for important insights in the case study design. Our RAND colleagues Jennifer Hawes-Dawson from the RAND Survey Research Group and Narayan Sastry also helped shape the design and implementation of the case studies. Other RAND staff who assisted with contacting respondents and conducting interviews included Andrea Mejia, Maren Leed, and Karen Swanson. Randall Hirscher provided invaluable programming support. We also benefited from the able production assistance of Barbara Thurston.

We also thank the 44 families who shared their experiences with us and the 80 agency administrators and providers who took the time to respond to our questions thereby providing the information upon which this report is based. We extend special thanks to the staff in the SSA offices.

ACRONYMS

Acronym	Definition
ADA	Americans with Disabilities Act
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
AFDC	Aid to Families with Dependent Children
ALJ	Administrative Law Judge
ASPE	Assistant Secretary for Planning and Evaluation (DHHS)
BBA	Balanced Budget Act of 1997
CCS	California Children Services
CFR	Code of Federal Regulations
CDR	continuing disability review
CE	consultative exam
CR	claims representative
CSHS	Children's Special Health Services (Louisiana)
DA&A	Drug addiction and alcoholism
DCF	Department of Children's Services (Connecticut)
DCFS	Department of Children and Family Services (California)
DDS	Disability Determination Service
DED	Disability Evaluation Division, Department of Social Services (California)
DHHS	Department of Health and Human Services
DHO	Disability Hearing Officer
DHU	Disability Hearing Unit
DMH	Department of Mental Health (California)
DPSS	Department of Public Social Services
DQB	Disability Quality Branch
FBR	federal benefit rate
FIA	Family Independence Agency (Michigan)
FITAP	Family Independence Temporary Assistance Program (Louisiana)
FO	Field Office (SSA)
FPL	federal poverty level
FTE	full-time equivalent
GA	General Assistance
GAO	General Accounting Office
HCFA	Health Care Financing Administration
HOTS	Hearing Officers Temporary Staff
IEP	Individualized Education Plan
IFA	individualized functional assessment
IVT	Interactive Video Training
LAUSD	Los Angeles Unified School District
LBW	low birth weight

MDW	Manual Development Worksheet
MIS	management information systems
MOU	memorandum of understanding
MPAS	Michigan Protection and Advocacy Services
MR	mental retardation
MSIS	Medicaid Statistical Information System
NCYL	National Center for Youth Law
OFS	Office of Family Support (Louisiana)
OHA	Office of Hearings and Appeals
PHP	prepaid health plan
PL	Public Law
PRWORA	Personal Responsibility and Work Opportunity Reconciliation Act of 1996
SCHIP	State Child Health Insurance Program
SED	severe emotional disturbance
SIPP	Survey of Income and Program Participation
SR	service representative
SSA	Social Security Administration
SSI	Supplemental Security Income
TANF	Temporary Assistance to Needy Families

1. INTRODUCTION

The report is divided into eight sections. Section 1 provides an overview of the background and policy changes to the SSI childhood disability program. Section 2 describes the methodology used to design and implement the case studies. Sections 3 through 7 provide detailed site visit reports for each of the five sites, with results from agency interviews (SSA offices and Medicaid agencies, and several other public or private agencies) and family interviews. The sites are presented in the following order: Los Angeles, Fresno, Hartford, New Orleans, and Detroit. Each of these sections begins by describing characteristics of the SSI child caseload in 1996 and highlights characteristics of TANF, Medicaid, and SCHIP programs that were in place during the study period. Section 8 provides a synthesis of our findings by summarizing key findings from the final interviews and highlighting key findings from the 1998 interviews. The overall conclusions from the case studies are presented in the final section along with the questions raised for further evaluation. An Appendix provides additional detail about the redetermination process that resulted from the 1996 welfare reform and the subsequent policy changes in the 1997 BBA and the Commissioner's Top-to-Bottom review.

1.1 BACKGROUND OF THE SSI CHILDHOOD DISABILITY PROGRAM

The SSI program is a federally administered program to assist low-income elderly, blind, and disabled individuals. It was enacted in 1972 under Title XVI of the Social Security Act. Until recently, the Social Security Act did not have a separate definition of disability for children. A child under age 18 was considered disabled if he or she had a "medically determinable physical or mental impairment that is of comparable severity to an impairment that would disable an adult (SSA, 1995). Before 1990, children qualified for SSI if their condition met or was judged to be medically equal to a condition listed in the regulations or to a special listing of children's impairments (Part B of the Listing) (CFR 404 and 416, 1996). Unlike adults, children who did not have a listed condition were not then individually assessed for their "residual functional capacity."

Several important modifications were made in the early 1990's to SSA regulations on the disability determination process for children. First, in response to the Social Security Disability Benefits Reform Act of 1984 (DBRA), PL 98-460, SSA modified the Listing of childhood mental impairments through new regulations issued in December 1990. The number of mental impairment codes was augmented from 4 to 11 conditions to reflect an evolution in the diagnosis and treatment of childhood mental impairment. The mental impairment listings were expanded to include attention-deficit/hyperactivity-disorder and were more functionally based on the child's ability to perform age-appropriate activities, such as interaction with peers (Aron, Loprest and Steuerle, 1996).

The February 1990 Supreme Court decision *Sullivan v. Zebley* had an even more significant impact on children's eligibility for SSI. This decision found that the absence of

individual assessment of function in children violated the SSI statutes, as did the failure to provide adequate evaluation of children with unlisted impairments or with combinations of impairments that did not fulfill all criteria for any one listed impairment (Zebley, 1990). SSA issued new regulations in February 1991 that explicitly defined comparable severity in childhood as an impairment that affects a "child's ability to grow, develop, or mature physically, mentally, or emotionally" and that limits the child's "ability to function independently, appropriately, and effectively in an age-appropriate manner" (SSA, 1995). Regulations issued after *Zebley* stated that children whose impairment was not found to be medically equivalent to a listed impairment would next be evaluated under an individualized functional assessment (IFA) to determine if the impairment met the comparable severity standard. Depending on the child's age, the evaluation included an assessment of some or all of a set of functional domains: cognitive and communicative, motor, social, and personal/behavioral functioning, and task completion (concentration, persistence, and pace). All child eligibility determinations made between 1980 and 1991 were redetermined using these new post-*Zebley* criteria (Aron, Loprest and Steuerle, 1996). These criteria were used for child SSI applicants until the 1996 welfare reform was enacted.

Between 1989 and 1996, the total number of children receiving SSI increased from 296,000 to over one million (SSA, 1996). As the childhood caseload rapidly increased, the composition of the caseload also changed. For example, between 1989 and 1994, the percentage of child SSI recipients whose primary diagnosis was coded as mental retardation or as another mental impairment increased from 48 to 61 percent (National Commission on Childhood Disability 1995). By 1996 more than two-thirds of child SSI recipients were eligible because of a mental impairment (SSA, 1997). The growth in child SSI recipients has been attributed to the 1984 DBRA changes, the 1990 *Zebley* decision, higher childhood poverty rates, and increased SSI outreach activities. As the childhood caseload grew, some raised concerns that the program was providing benefits to children whose impairments did not warrant such benefits or whose medical conditions had improved since SSI was initially awarded. A 1995 Report to Congress by a National Commission on Childhood Disability recommended a number of changes to the SSI program. Examples of these recommendations included the following: requiring that lump-sum benefits be used for the child's impairment; continuing Medicaid eligibility for children who lose SSI due to medical improvement; requiring periodic continuing disability reviews for children whose status may improve; requiring appropriate treatment where available and affordable; substituting more detailed surveys of health needs and use of benefits for annual family reporting requirements; and strengthening the definition of childhood disability. Several reports by the General Accounting Office (GAO, 1995) in the 1990's described the increasing caseload and identified the need for periodic re-evaluations of disability in children since the severity of some impairments might decline as the child grew older.

1.2 OVERVIEW OF THE 1996 CHANGES TO CHILDHOOD SSI ELIGIBILITY AND RELATED POLICY CHANGES

The Personal Responsibility and Work Opportunity Reconciliation Act (PL 104-193), which was signed into law by President Clinton on August 22, 1996, changed the determination of childhood disability by providing a new statutory definition of disability for children applying for SSI. As a result of the welfare reform law, 264,000 of the approximately one million child SSI beneficiaries received informational notices in November and December of 1996 stating that they were subject to eligibility redetermination. Welfare reform provisions subjected children who were found not to meet the new disability criteria to loss of SSI benefits beginning in July 1997.

The welfare reform law changed the criteria for childhood disability in new applicants and also established an eligibility redetermination process for certain groups of child SSI recipients. Under the law, the comparable severity criteria was replaced with a definition of disability unique to children: "a medically determinable physical or mental impairment, which results in marked and severe functional limitations" (SSA, 1997). The legislation eliminated the individual functional assessment (IFA) that was created following the *Zebley* decision. SSA created a three-step evaluation process to assess the functional equivalency of an impairment to conditions in the Listing of Impairments (in Appendix 1 of Subpart P of 20 CFR Part 404, called "the Listing"). Functional equivalency for children was modified under the new SSI eligibility standards to require at least two marked limitations for a child. In addition, the Listing for childhood mental disorders (112.00C2 and 112.02B2c) was modified to remove references to maladaptive behavior from the personal/behavioral domain.

Welfare reform provisions affected two additional groups of child SSI recipients. Eligibility for children reaching 18 years of age must be evaluated using the SSI criteria for adult disability. Children under age 18 who have impairments that are considered likely to improve must be reviewed at least once every three years in a continuing disability review.

Children were subject to redetermination if their SSI eligibility had been allowed based on an IFA or based on maladaptive behaviors in the mental disorders listings. Children also were subject to redetermination if they had been allowed at the Listing level and the determination had involved any of four maladaptive behavior impairments (personality disorder, attention deficit/hyperactivity disorder, conduct disorder, or oppositional defiant disorder).

The welfare reform provisions stated that the redeterminations must be completed within a year of the law's effective date. Consequently SSA worked toward completing the redetermination process by this imposed deadline of August 1997. The time period required new regulations to be quickly implemented and also imposed heavy workloads on SSA offices. The time period for the redetermination process was extended an additional six months by the 1997 Balanced Budget Act (discussed in more detail below). This change extended the effective deadline to February 1998. Policy implementation procedures are described in greater detail in Appendix A. A very brief overview of the redetermination steps includes the following. Children whose eligibility was subject to

redetermination were notified of the upcoming redetermination process. Families were notified of their appeal options should the child's SSI benefits be ceased and were informed of their option to obtain legal assistance. Notices to families included hotline numbers for local legal assistance. SSA worked with the American Bar Association (ABA) after welfare reform was passed to establish legal support for families whose children were affected.

Cases ceased after the initial review could be appealed within 60 days and benefit payment continuation could be requested by the family within 10 days of the notice of cessation. Appealed cases were reviewed at a reconsideration level with a case file review and face-to-face hearing before a Disability Hearing Officer (DHO). Subsequent levels of appeal (based on cessation at the previous level) include hearings before an Administrative Law Judge (ALJ), then appeal to the Appeals Council, and finally a filing of a civil action in federal court. For welfare reform provisions regarding children at age 18, redeterminations were undertaken with similar notification and appeal opportunities for families.

The 1997 Balanced Budget Act (BBA) was passed one year after the welfare reform law. The BBA included several provisions that related to child SSI recipients. One provision was the "grandfathering" of Medicaid eligibility for children who lost SSI after their eligibility was redetermined under welfare reform criteria. In most states, children who receive SSI become automatically eligible for Medicaid. Prior to the 1997 BBA, children who lost SSI would no longer be automatically eligible for Medicaid based on SSI eligibility. The BBA conferred Medicaid eligibility for children who were receiving SSI on August 22, 1996 and who effective July 1, 1997 (or later) lose SSI because of a disability determination under the rules enacted by the 1996 welfare reform.³ This provision encompasses children under 18 years of age. It does not apply to SSI beneficiaries who have reached age 18 and whose SSI eligibility is being redetermined under adult criteria.

Pursuant to the 1997 BBA, SSA provided the States with at least three lists of children whose SSI benefits were ceased due to welfare reform redeterminations. These lists were made available to enable States to evaluate Medicaid eligibility based on the BBA "grandfathering" provision or under other Medicaid eligibility aid categories if BBA

³Children living in States that do not provide Medicaid eligibility to children based on disability, or in States that use the more restrictive disability definition permitted by Section 1902(f) of the Social Security Act, are not affected by this provision; also, a child who loses SSI after August 22, 1996 for a non-disability reason does not have protected Medicaid eligibility under this provision (HCFA, November 13, 1997). Following the 1997 BBA, HCFA began working with SSA to determine whether SSA medical evidence could be made available to States to facilitate determination of whether a child covered by the provision meets disability requirements in effect prior to August 22, 1996 (HCFA, November 13, 1997). HCFA has issued guidance to States on their responsibilities in implementing BBA "grandfathering" provisions and on the use of SSA lists made available for this purpose (HCFA, October 2, 1997).

protections did not apply to a child. (The regular monthly updates on entering and exiting SSI beneficiaries continue to be provided by SSA directly to state Medicaid agencies, through the State Data Exchange (SDX) system.)

Another relevant provision of Section 2101 of the 1997 BBA was the new State Children's Health Insurance Program (SCHIP) enacted as Title XXI of the Social Security Act. SCHIP provides federal funding to States to expand Medicaid eligibility for low income children and to create separate (non-Medicaid) child health insurance programs for low-income children ineligible for Medicaid. Further detail on BBA changes to childhood disability determination is provided in Appendix A.

In the Fall of 1997, Commissioner Apfel initiated a "Top-to-Bottom" review of the implementation of the childhood disability redetermination process. The results of that review were made available in the Commissioner's Report that was released in December 1997 (SSA, December 17, 1997). This review identified four additional changes in the redetermination process that SSA would undertake. First, the appeals and benefit continuation process was reopened, with a new 60-day appeals period (and a new 10-day period to request benefit continuation) for cases where benefits had been ceased and no appeal had been filed. Families who had appealed without requesting benefit continuation were given a new 10-day period in which to request that benefit payments continue during the appeal. Families who had not appealed a cessation or who had appealed but had not requested benefit continuation during appeal were notified of their opportunity (through the Reappeals and Benefit Continuation letter frequently referred to as the "good news" letter, which contained simplified language in English and in Spanish). This provided another opportunity to families who may not have understood their appeal and benefit continuation options.

Second, SSA undertook a review of all cases ceased after redetermination that involved coding for a primary diagnosis of mental retardation (MR). SSA also reviewed initial denials that occurred after August 22, 1996 that showed coding for mental retardation. This was due to concerns that some redeterminations in mental retardation cases might have incorrectly resulted in cessation. Due to the lack of specific case coding for mental retardation in the SSI program prior to welfare reform, not all of these redeterminations were expected to actually involve mental retardation. Third, all cessations based on a "failure to cooperate" were also to be reviewed to ensure that the cooperation of a child's family had been fully sought and these efforts documented. Finally, SSA undertook a further quality review process to examine cases in each Disability Determination Service (DDS) office with a high likelihood of error based on quality assurance data. Appendix A provides additional detail regarding the actions that followed the Commissioner's report.

Overall, SSA estimated that as a result of the actions directed by the Commissioner, 100,000 of the approximately 264,000 children subject to redetermination will lose their benefits after all appeals have been completed. This was revised downwards from the initial estimate of 135,000 children who would lose benefits as a result of the 1996 welfare reform legislation.

1.3 OBJECTIVES AND APPROACH OF THE CASE STUDIES

The welfare reform law was a significant change that affected a large number of low-income children. SSA contracted with RAND to assess the effects of welfare reform SSI provisions on children who have lost or may lose SSI disability benefits. The qualitative component of the “Policy Evaluation of the Effect of the 1996 Welfare Reform Legislation on SSI Benefits for Disabled Children” was designed to provide information on the progress of the redetermination process and to evaluate its impact on affected children and their families. The purpose was to obtain qualitative information on how the law affected the lives of former child SSI recipients in terms of income, living arrangements, alternative sources of income support, and access to medical care. The qualitative component also was designed to provide information on the support systems being used by children who would have been eligible for SSI in the absence of the 1996 welfare reform.

There are few national data sources that provide timely public use survey data on this population of children at a nationally representative level or data sources that provide state-level estimates of policy impact. The case study methodology was employed to identify a range of experiences and responses of families, SSA offices, and agencies across several localities with diversity in geography and in potentially important policy characteristics. This qualitative component of the policy evaluation was not designed to produce nationally representative information on policy impact or to draw conclusions about the policy's overall impact in the States and localities that participated in the study. The qualitative findings provide local perceptions and detailed, illustrative descriptions of how families are responding to and are affected by the SSI eligibility changes. Another important objective of the case study is to generate hypotheses that can be tested in the quantitative analyses of this evaluation and used to interpret the results of the quantitative analyses.

The qualitative data were gathered in two rounds of interviews approximately one year apart. The primary focus of the first round of case studies was to describe the perceptions and experiences with policy implementation and the initial responses of families to the potential loss of SSI. The second round of case studies focused on perceptions and experiences later in the implementation process and on changes that occurred after more time elapsed following loss of SSI.

The case studies focused on several domains of possible impact. We focused on the support systems used by children with disabilities and on likely determinants of health care access and family income dynamics. Possible determinants of health care access include health insurance, participation in managed care/prepaid health plans (PHPs) due to

Medicaid requirements or commercial health insurance options and provider choice. Determinants of family income include parent work participation and use of public income assistance, among others. The second round of case studies focused on the outcome of the SSI eligibility redetermination and on the following domains of child and family impact:

- **Response to the policy implementation.** How did families respond to the eligibility redetermination process, and what choices did they make in terms of appeals, benefit continuation, and use of legal assistance?
- **Medicaid enrollment and access to medical care.** Was the loss of SSI associated with changes to children's Medicaid eligibility and to Medicaid enrollment, and with changes in access to health care?
- **Impact of health care arrangements.** Did changes in SSI eligibility affect children's participation in fee-for-service versus managed care Medicaid arrangements and has participation in Medicaid or commercial managed care affected children's access to care?
- **Effects on family income.** What happened to family income and use of public income assistance programs after children's SSI benefits were ceased? What changes occurred in the employment status and earnings of the children's primary caregiver(s)?
- **Effects on living arrangements.** How has the loss of SSI eligibility affected the living arrangements of children and their families, including household moves and entry into foster care?

In addition, the case studies addressed the policy's impact on local SSA offices and examined the perceptions of agencies within the local support systems for children with disabilities. To provide a context for understanding family experiences with and responses to SSI loss, we examined the following domains of policy impact with local agencies

- **Effects on SSA offices.** How have SSA offices been affected by the policy changes, and what have been the major challenges to implementing the childhood SSI changes?
- **Effects on other agencies serving children with disabilities.** How have some of the public agencies that serve children with disabilities responded to and been affected by the changes to childhood SSI eligibility?
- **Observations of family impact.** What effects on children and their families were observed or anticipated? How did the local organization and availability of public assistance, health care, and mental health services contribute to the policy's impact on children who lose SSI and on their families?

The two rounds of case study interviews were conducted in five sites: Los Angeles and Fresno, California; Detroit, Michigan; Hartford, Connecticut; and New Orleans, Louisiana. In this report, we present our findings for the second round of interviews conducted in September and October of 1999. Across the five sites, we interviewed 35 of the 44 families who participated in the first round of case studies in 1998. We also visited several SSA offices and state agencies in each of these sites. Interviews with regional and field SSA offices provided information on administration of the redetermination and appeals processes for childhood SSI beneficiaries. Interviews with agencies other than SSA provided a broader perspective on the impact of the SSI childhood eligibility changes for the local community. State, local, and private agencies who were interviewed included organizations such as the state Medicaid agency, social service agencies that administer public assistance and family work programs, child protective services agencies, advocacy organizations, and other organizations that provide services to children with disabilities.

The findings from the second round of case studies reflect the impact of welfare reform as perceived by families. The findings also provide insight into the major implementation issues and challenges for SSA offices. We sought the perspectives of administrators in a range of other public agencies that serve children with disabilities to identify possible effects. The experiences reported by families and by agencies that serve children with disabilities help to illustrate the types of effects that may be seen in other communities. These experiences also illustrate the needs of the affected children that their families consider to be unmet. The five sites were selected to provide variation in the implementation and impact of the policy changes. While the case studies provide a detailed picture of the legislative impact, the findings should be interpreted with caution. Although there is significant variation in health and social service systems and geographical diversity across the selected sites, the findings from the selected sites cannot be generalized to other locations.

2. CASE STUDY METHODOLOGY

In this section, we describe the methodology of the case study component of the evaluation of the impact of the 1996 welfare reform legislation on disabled children receiving SSI. Further detail of the sampling rationale and procedures is provided in the first round report (Inkelas et al., 1999). In particular, we discuss the rationale for the selection of the five sites and a description of the policy environment for the selected sites. We then discuss the protocols for conducting interviews with SSA offices and other government agencies and for conducting interviews with families of affected children. We also discuss the strengths and the limitations of the study design.

2.1 SELECTION AND CHARACTERISTICS OF CASE STUDY STATES

2.1.1 Rationale for Site Selection

The policy evaluation called for case study visits in four states. Given the limited number of sites to be visited, the selection of states was not intended to provide a statistically representative sample. We selected states that differed across dimensions that were relevant to children receiving SSI to maximize the amount of variation that would be observed across the case study sites. The purpose of this strategy was to provide a diverse portrait of the perceptions and experiences of families and service providers in several different sites across the U.S.

We considered the following criteria for selecting the state sites for the case studies:⁵

- 1) SSA administrative region;
- 2) Absolute size of the SSI caseload;
- 3) Participation rate in SSI;
- 4) Frequency of IFA and maladaptive behavior cases within the SSI caseload;
- 5) Continuation rates from the initial redeterminations;
- 6) Existence and generosity of state supplementation of SSI benefits;
- 7) Existence and nature of state Medicaid policies for managed care.

⁵There are clearly other indicators that could have been added to the list, although with only four case study sites to be selected, there is a limited number of variation that can be achieved. Nevertheless, we believe the criteria delineated here represent the most salient dimensions along which states vary that are relevant to child and family outcomes

By selecting states in different SSA administrative regions, we were likely to detect variation in SSA policies with respect to program administration and implementation of the new disability determination criteria. The set of criteria listed above also led to variation in the overall size, participation rate, and composition of the SSI caseload. These parameters may have implications for the ability of SSA staff and the adjudication process to handle the transition to the new rules. These factors also may affect the ability of local social service providers to make up for the loss of SSI benefits among the affected families. Finally, the implications of losing SSI benefits are likely to vary depending on the generosity of the state's SSI cash assistance levels, the way in which Medicaid services are provided to both SSI and non-SSI program participants, and the availability of social services for low-income families.

Based on these criteria, we selected the following four states: California, Connecticut, Louisiana, and Michigan. Each state represents a different SSA administrative region (San Francisco, Boston, Dallas, and Chicago, respectively), and these four states also capture much of the important variation that is likely to affect the direction and magnitude of the impact of the 1996 welfare reform legislation on families. The following section illustrates this variation by providing additional detail on the selected criteria for each of the four case study states.

2.1.2 Caseload and Redetermination Characteristics of the Case Study States

The absolute SSI childhood caseload size as of December 1996 varied significantly across the selected case study states, ranging from one of the highest state caseloads in the country (California) to one of the lowest caseloads (Connecticut). There were sharp differences as well in underlying SSI participation rates. These rates ranged from 0.7 percent of the childhood population in Connecticut to 3.1 percent of children in Louisiana. These differences reflect in part the underlying differences in child poverty rates that ranged in 1995 from a low of 13.6 percent in Connecticut to 31.3 percent in Louisiana.

The proportion of the SSI caseload with eligibility related to IFA or maladaptive behavior—the groups most affected by the new eligibility criteria—also varied considerably across the four states. Two extremes in IFA caseload shares are represented by California (14 percent) and Michigan (31 percent) compared to 23 percent nationally. Variation in maladaptive behavior rates ranged from one (1) percent in Connecticut to six (6) percent in California compared to 4 percent nationally. This variation may reflect differences in the underlying incidence and identification of disabling conditions among the population of children in each state, as well as differences in the practices and incentives of the states with respect to SSI enrollment (Perrin and Stein, 1991).

The initial continuation rates differed substantially across the four states as well. As of November 1997, Louisiana's initial continuation rate (23.1 percent) was approximately 40 percent of California's rate (59.3 percent). These two states represent the extremes of the range in initial continuation rates across states. The initial continuation rates for Connecticut (43.4 percent) and Michigan (51.3 percent) were intermediate.

2.1.3 Policy Environment in the Case Study States

Several characteristics of the policy environment varied considerably among the four states. All four states supplement the federal SSI payment. The average state supplement (whether federally or state administered) ranged from \$69 in Louisiana to \$263 in Connecticut. Such differences in the SSI payments suggest that the consequences for families of losing SSI income are likely to differ across these states.

Another key dimension considered in the selection of case study sites was policy characteristics of the state Medicaid programs. The features of a state's Medicaid program are relevant to children on SSI who receive health insurance coverage through Medicaid. One feature is the automatic eligibility for Medicaid that is conferred by SSI eligibility. All case study states with the exception of Connecticut confer Medicaid eligibility to SSI recipients. Managed care participation requirements are another feature of state Medicaid programs that is relevant to children with disabilities. The Medicaid managed care provisions in some of the selected states include exemptions for SSI beneficiaries while other states require participation for all Medicaid beneficiaries. For example, in most California counties, enrollment in managed care arrangements is voluntary for children with SSI-linked Medicaid eligibility but mandatory for most other children receiving Medicaid. Managed care participation is a potentially important outcome for children with disabilities because managed care can provide greater service organization but also can restrict access to specialists and to providers of choice.

Finally, although we did not specify additional criteria in selecting these four states, there are other important dimensions along which these sites vary. These dimensions include the state or local economy and the eligibility criteria for other social support programs. These programs include the State Child Health Insurance Program (SCHIP) and the Temporary Assistance to Needy Families (TANF) program.

Although the Title XXI State Child Health Insurance Program (SCHIP) expansions of health insurance to children were still under development when case study sites were selected, the sites varied significantly in terms of the SCHIP options that have been adopted. Three of the states expanded Medicaid eligibility and also created a separate program for low-income children. Connecticut expanded Medicaid eligibility to 300 percent federal poverty level (FPL) through age 18 years and with a premium buy-in provision for families above 300 percent FPL.

The selected case study states also adopted a variety of different provisions pursuant to the 1996 welfare reform changes to the Aid to Families with Dependent Children (AFDC) program. Both Michigan and Connecticut were further along than other states in implementing key reforms and in imposing work requirements and time limits for public assistance recipients. Michigan and California imposed more liberal lifetime time limit provisions that did Connecticut and Louisiana, which adopted time limits under 60 months. Connecticut and California have longer transition coverage provisions for child care and for Medicaid coverage, both extending past 12 months. Transition child care following cessation of TANF benefits is provided to families in California and Connecticut but not in Louisiana and Michigan.

2.2 SELECTION AND CHARACTERISTICS OF LOCAL SITES WITHIN CASE STUDY STATES

Within the four selected case study states, we selected one local study site (county) in each state. Two sites were selected in California to provide for local variation within the state and to include one more rural location in the study. We chose to have two case study sites in California because of the state's geographic diversity and because there is variation in the social services system within the state. Many social service programs in California are administered by county government (e.g., general income assistance, Medicaid eligibility, child protective services).

Several of the selection criteria used for selecting case study states were applied for choosing local study sites within each state, including:

- 1) Overall SSI childhood caseload and participation rate in the program for children under 18;
- 2) Absolute size and rate of IFA and maladaptive diagnoses in the redetermination caseload;
- 3) Caseload subject to redetermination and the size of the affected caseload relative to the total SSI childhood caseload; and
- 4) Absolute number and rate of cases ceased and not under appeal as of January 31, 1998.

In addition, we examined the characteristics of counties based on an urban-rural continuum measure. This measure was used to differentiate counties with major urban areas from those with smaller urban centers or a largely rural composition.

We ranked counties on the basis of these indicators to determine which counties were most affected by the 1996 welfare reform legislation. Based on these criteria, the localities selected were Los Angeles and Fresno in California, Hartford in Connecticut, Orleans in Louisiana, and Wayne in Michigan.

As discussed earlier, the selection of States and subsequently of counties was conducted to capture some of the potential variation in policy impact across different service systems and geographic areas and characteristics. Given the significant variability across the sites based on specific site selection criteria, the sites were likely to reflect some of the differences in experiences and impact that may occur across communities nationally. However, the study design and site selection was not designed to provide a nationally representative group of sites.

2.3 INTERVIEWING PROTOCOLS FOR SSA AND OTHER AGENCY STAFF

2.3.1 Identifying, Contacting and Interviewing Agency Staff

In the first round of case studies, interviews with SSA office staff began at the Regional SSA Offices associated with the region of each of the case study sites and then proceeded to the state disability determination services (DDS) office and to one of the SSA field offices within the local area. In the first round of interviews, a field office with one of the highest absolute childhood SSI caseloads was selected. Similar contact procedures were used in the second round of interviews, with the exception that contacts in the various agencies had already been identified.

In each site, we also identified other public and private agencies that were likely to provide substitute income, health care, and other support services (e.g., special education programs) to children with disabilities, or that were likely to experience effects associated with the lost benefits for disabled children (e.g., child welfare agencies). Our listing of contact organizations include the local Title V Children with Special Health Care Needs agency, the department of social services and/or the local Medicaid eligibility office, the child welfare agency, and one or more other local organizations providing services to disabled children. The process for contacting individuals and conducting interviews was similar for these agencies.

When possible, interviews were conducted in person during the site visits (with the exception of SSA Regional Office interviews). Telephone interviews were conducted when scheduling difficulties precluded in-person interviews. An interviewing team of two individuals conducted the agency and family interviews. One member of the interviewing team participated in all agency and family interviews to increase consistency in interview format and content. All members of the case study team reviewed interview protocols and contact procedures to improve the design and consistency of the interview approach.

2.3.2 Content of Agency Interviews

The goal of the interviews with SSA office staff and with staff in other public and private agencies was to identify the perceptions and experiences of these individuals with the impact of welfare reform on child SSI recipients. We examined staff observations on the issues that arose in the process of policy implementation, the impact on agency operations, and the impact on affected families and children. The interview content and relative emphasis on particular topics varied among the providers and agencies interviewed. The general topics are outlined in Table 2.1.

Table 2.1
Topics for Agency Case Study Interviews

Agency/Provider Interview Topics
Description of the agency
Agency role in policy implementation
Impact on the agency and challenges
Perceptions of observed and future impact on children and families
Local policy and resource trends

The purpose of our interviews with local agencies that serve children with disabilities was largely to provide a service system context for the experiences that were reported by families. These interviews with other public and private sector agencies were used to characterize the services and programs that are available for children losing SSI benefits. Examples of areas covered include the extent to which changes in SSI eligibility rules for disabled children might affect participation in publicly funded programs such as the foster care/child protective service system, special education systems, and public assistance programs. Agency administrators also were asked for their observations on how welfare reform provisions regarding SSI had affected their agency or the populations they served. Specific topics included current or future program participation, caseload composition, and unmet need.

2.4 INTERVIEWING PROTOCOLS FOR FAMILIES

This section first summarizes the sampling and contact procedures for the first round of case studies and then describes the re-contact and follow-up procedures undertaken in the second round. Further details on the sampling and contact procedures are provided in the first round report (Inkelas et al., 1999).

2.4.1 Identifying Families

For the first round of interviews, we selected a clustered sample of families based on zip codes of residence within each case study site. The objective was to ensure that the experiences reported by families would relate to the information reported by SSA offices and by local agencies. The sample was drawn from a sampling frame of all children in these geographic areas who were receiving SSI in August 1996 and whose SSI eligibility was being redetermined based on the new childhood disability standard. The sampling frame included affected children in the local geographic area who were identified from the SSA Universe File (as of January 31, 1998).

To capture some variability in family experiences across important child characteristics (age and type of impairment), we categorized children into strata based on the age of the child and based on three medical diagnosis classifications from impairment type coding available in the Universe File. The three classifications were the following: (1) cases coded as involving mental retardation; (2) cases coded as a mental

health/psychiatric disorder (including schizophrenia and other mental disorders); and (3) cases coded as a physical health impairment (such as infectious diseases, nervous system disorders, congenital anomalies, asthma, etc.) or an impairment in the "other" or missing category. Age categories included under 6 years, age 6 to 11 years, and age 12 years and older.

We constructed 7 strata and used a different interviewing protocol (with some common core elements) for each stratum. Due to the relatively small number of children age 0 to 5 years of age in the sampling frame, children 0 to 5 years identified in any medical diagnostic category were combined into one stratum. The strata were (1) children 0 to 5 years (any diagnostic category), (2) children 6 to 11 years with coding for mental retardation, (3) children 6 to 11 years with a mental health/psychiatric classification, (4) children 6 to 11 years with a physical health or "other" classification, (5) children 12 to 18 years with coding for mental retardation, (6) children 12 to 18 years with a mental health/psychiatric classification, and (7) children 12 to 18 years with a physical health or "other" classification. We sought approximately equal numbers of respondents in each of the strata. Variation in caseload distribution and in family response rates across the sites resulted in a range of 4 to 8 children per stratum. Given the small number of families interviewed within the strata, the case study design in this evaluation does not require clearance by the Office of Management and Budget (OMB) under the Paperwork Reduction Act.

2.4.2 Procedures for Contacting Families in the First Round (1998)

In the first round, a random selection of potential respondents from each local sampling frame were contacted by mail. The letters were followed by a telephone call to the residence whenever a phone number was available. If we reached a household by telephone where the family no longer lived and a forwarding telephone number was obtained, then an attempt was made to contact the family at this new number.

Children whose representative payee was an agency (e.g., child protective services) or institution (e.g., Medicaid institution) were excluded from the study because there was no parent whom we could contact directly. When our telephone contact with the family revealed that the child was in out-of-home foster care or institutionalized, no interview was attempted if the contacted parent said that they would not be able to answer detailed questions about the child and about the SSI eligibility redetermination process for the child.

Families were excluded if neither parent spoke English and no other adult relative or friend could be identified to assist in the translation. This eliminated a total of four families in two sites who were Spanish-only speaking. We did interview four non-English speakers with translation assistance from a family member or friend. Thus the perspectives of several non-English speaking parents or guardians are included in the findings from family interviews. In summary, we excluded families from participation if the child was (1) in foster care with an agency payee at the time of the attempted interview; (2) living in a different household than the contacted parent payee, when the

parent did not have current information on the child's health status and SSI eligibility status; or (3) living in a non-English speaking family with no adult translator available.

The proportion of families whom we successfully contacted by telephone ranged from 14 percent in Hartford to 40 percent in Los Angeles. Those who were contacted but not interviewed included several families who refused to participate, several Spanish-only speaking parents, and two families for whom an interview was scheduled but not completed. The response rates for the sample are low. Such low contact and response rates have been found in other studies that based their sampling frames and contact information on administrative data sources such as public income assistance data. Low rates are not surprising due to the mobility of public income recipients and due to changes in telephone numbers or the use of telephone numbers of family members or friends. Given the low response rates, it is likely that those families whom we were unable to contact may differ systematically from those families we successfully contacted. Such low response rates may bias results when nonrespondents differ systematically from respondents, particularly if they differ on characteristics such as current income and residential stability, or the child's prior or current functional status.

While these are important considerations, it is also important to reemphasize that the intent of the study design was not to draw conclusions from a representative and statistically adequate sample. The limitations in the generalizability of the findings due to the scope and selection of sites, and in the representativeness of the family interviews due to potential response bias, can be viewed in relation to the specific study objectives. Key objectives were to identify a range of possible effects that other administrative and survey data do not provide, and to identify questions that could be tested in the quantitative analyses. Findings from the family interviews continue to be useful for these purposes even though they are not representative of family experiences nationally and do not represent all possible family experiences and outcomes.

To minimize loss of family participants between the initial round of case studies and the second round, we requested that each family provide one or more names with contact information of relatives, neighbors, and/or close personal friends whom we could contact if the family moved during the year. Families were told they would be re-contacted by mail at the end of 1998 and by phone in Spring 1999 to confirm their address and phone or to obtain updated information.

2.4.3 Characteristics of Children and Families Interviewed in Round One (1998)

As noted earlier, the caseload was divided into 7 sampling strata based on age and coded diagnosis category with a different interview protocol for each strata. The final distribution of the 44 families interviewed across these strata is shown in Table 2.2. The sampling frame totals refer to the number of children who resided in the selected zip codes within the sites and who could be identified from the SSA Universe File (as of January 31, 1998) as undergoing SSI eligibility redetermination based on the new childhood disability standard. This table also illustrates the distribution of affected children by strata within the aggregate of local sites as of August 1996.

The payee for most of the children (36 cases) was the child's mother. In two cases, the father was the payee and the guardian of the child. The child's grandmother and current guardian was the payee in five cases. The child's great-grandmother was the current guardian and payee in one case.

Table 2.2
Totals in Interview Sample by Strata
(Aggregated Across Sites)

Age (as of 8/96)	Diagnostic Category							
	Any Diagnosis		Mental Retardation		Mental/ Psychiatric		Physical or Other	
	No.	%	No.	%	No.	%	No.	%
Sampling frame								
Under 6 years	69	9%	--		--		--	
6 to 11 years	--		85	11%	162	21%	81	10%
12 years and older	--		112	14%	189	24%	84	11%
Interview sample								
Under 6 years	7	16%	--		--		--	
6 to 11 years	--		7	16%	4	9%	7	16%
12 years and older	--		8	18%	7	16%	4	9%

2.4.4 Contact Procedures for Families in the Second Round (1999)

We initiated the re-contact procedures for families who participated in the first round, using two sets of letters sent in Winter and Spring 1999. A telephone follow-up call was placed to each family in Spring 1999. For those families who could not be contacted at their home telephone number, and for those families whom we knew did not have telephones in the home, we initiated contact by telephone and/or by mail with one or more of the family friends or relatives whose names had been provided to us in the first round interview. The purpose of these contacts was to confirm the contact information and also to remind the families that we would be re-contacting them for a follow-up interview. We also reiterated that they were not required to participate in the second round interviews. Another set of letters was mailed to those families whom we were unable to contact or to the contact name(s) that the family had provided.

To minimize attrition of first round participants, we attempted to update our contact information using more recent SSA data. We compared contact information for those families from the first round whom we were unable to successfully re-contact with the potentially more current telephone and address information supplied by SSA in Fall 1999.

The source was an extract of the Universe File more recent than the January 31, 1998 file used to identify the original sample. We recognized that those children who left the SSI rolls may not have more recent contact information in the data provided by SSA. To protect confidentiality of the participating families, the interviewing team obtained last known contact information (name, telephone, and address) for the full initial sample rather than for only those families for whom the information was needed.

Several weeks prior to the beginning of each second round case study site visit, we initiated telephone contact with each family. If we did not have a valid telephone number, we sought the telephone number from directory assistance. Overall, about 5 families (or their contact) could not be reached by telephone prior to the site visit. For several families who could not be reached by telephone prior to the site visit, the interviewing team went to the home address to leave a card with the project and interviewer names and the toll-free telephone number. There were two exceptions. In Los Angeles, the two families that could not be contacted by telephone were known (by return mail) to no longer reside at the 1998 address. In Fresno, the family that could not be contacted was known to have moved based on information provided by a contact.

To maximize participation in the second round, we conducted telephone interviews with three families who could not be interviewed during the site visit due to their work schedules or due to other family conflicts.

2.4.5 Characteristics of Children and Families Interviewed in Second Round (1999)

A total of 80 percent of the families who participated in the first round were re-interviewed in 1999. Table 2.3 shows the distribution across the sampling strata of children whose families could not be successfully re-interviewed in 1999. Loss to follow-up was evenly distributed across the strata.

Table 2.3
Loss to Follow-up for Interview Sample by Strata
(By Site and Coded Diagnostic Category)

Age (as of 8/96) and Coded Diagnostic Category	Total in Strata (1998)	Total Lost to Follow-Up (1999)				
		Los Angeles	Fresno	New Orleans	Detroit	Hartford
Under 6 years	7	0	0	0	0	1
6 to 11 years (Mental retardation)	7	1	0	0	0	1
6 to 11 years (Mental/Psychiatric)	4	1	0	1	0	0
6 to 11 years (Physical/Other)	7	0	0	0	1	0
12 + years (Mental retardation)	8	0	0	0	1	0
12 + years (Mental/Psychiatric)	7	0	1	0	0	0
12 + years (Physical/Other)	4	0	0	0	0	1

2.4.6 Family Interview Content

For each family interview protocol, we used semi-structured interview guides that focused on the key activities and outcomes of the 1996 policy change for childhood SSI eligibility. The first round of interviews had focused on the families' experiences with eligibility redetermination and on the initial family responses to potential or actual loss of benefits. The second round of interviews focused more intensively on the outcome of the redetermination process, the longer-run impact of the income loss, any changes in the family income or structure that occurred over the study period, the parent's current assessment of the child's health status and health needs, and access to and use of legal assistance. We generally used a baseline referent period as the time when the family was first notified of the SSI eligibility changes resulting from welfare reform. We used this time period as a referent for family responses so that families across sites would use a common anchor. We also asked families about changes occurring since SSI had been lost to capture policy impact.

While the interview content (and the emphasis within the interview) varied according to the family's strata classification, the general content of the family interviews is provided in Table 2.4. In addition to descriptive information about the child and family, the key content areas included the following experiences throughout the redetermination process; the impact on family income and work participation; the impact on the child's Medicaid enrollment and access to health care; and the overall impact on the child.

Table 2.4
Topics for Family Case Study Interviews

Family Interview Topics
Child's medical diagnostic information
Family's experience with SSI eligibility redetermination
<input type="checkbox"/> understanding of the process
<input type="checkbox"/> appeal and benefit continuation outcomes
<input type="checkbox"/> access to and use of legal assistance
Impact on family income
<input type="checkbox"/> family income
<input type="checkbox"/> work participation and working hours of caretaker(s)
<input type="checkbox"/> use of public assistance
Family structure and changes
<input type="checkbox"/> household composition
<input type="checkbox"/> child's living arrangements
Impact on Medicaid and health care access
<input type="checkbox"/> Medicaid enrollment/access to health insurance
<input type="checkbox"/> access to medical and developmental services
Impact on the affected child
<input type="checkbox"/> child care and caretaking
<input type="checkbox"/> parent/caretaker's time spent with the child
<input type="checkbox"/> child's developmental and functional status
<input type="checkbox"/> child's school performance
<input type="checkbox"/> child's preparation for work

All findings from the family interviews are based on self-reported information. This is particularly relevant to the information provided by families about the medical diagnoses and current functional status of the child; about family income; and about the appeals and benefit continuation requests that they might have made. Details provided by families about their requests for appeal, and requests for benefit continuation under appeal, have not been compared with SSA administrative records. While attempts were made in the interviews to anchor family responses about appeals to known dates such as the issuance of the 1998 "good news" letters, there might be some discrepancies between what families reported to us and what would be found in SSA records. For example, a survey conducted by SSA of over 400 beneficiaries who filed appeals but according to SSA records did not request benefit continuation revealed that "half of the people said they believed they had requested benefit continuation" (SSA, December 17, 1997, p. XX).

Open-ended questions to the family provided parents with an opportunity to describe the specific ways in which the child's or the family's lives have changed. Examples of the types of issues addressed in the interviews include:

- What changes have occurred in the child's health status and functional level since the loss of SSI income?
- What changes have occurred in the utilization of public health and mental health services, and in access to and use of personal medical and health-related services?
- Has the child enrolled in a commercial or managed care plan and has this enhanced or adversely affected the child's access to health care?
- What special school services are utilized and how has school performance been affected?
- What changes have occurred in the child's access to publicly-funded care coordination services for children with special needs such as social work, case management, early intervention, etc.?
- What changes have occurred or are anticipated in family structure and family living arrangements and location?
- How have changes in parent employment or working hours affected the child's time with the parent, use of child care, and access to services?
- How has family income changed since the redetermination process began and since benefit cessation or continuance occurred?
- Is the child or the family receiving other assistance (income, services) that substitute for the lost SSI income?

- How have parent working hours changed, if at all, since the SSI income was lost, and how are income and parent working hours expected to change in the future?

Finally, the family interviews were designed to provide a perspective on families' experiences with the redetermination and appeals process. To understand family perspectives on the redetermination process, we asked families what they understood and whether all aspects of redetermination were clear to them. Several questions focused on aspects of the process such as access to and use of legal assistance, and the consequences of the family's appeal and benefit continuation decisions, such as dedicated accounts or overpayment requirements.

2.5 STRENGTHS AND LIMITATIONS OF THE STUDY DESIGN

The case study methodology outlined in this section is designed to provide insight into the impact of the 1996 welfare reform legislation on the families and children affected by the loss of SSI income. The descriptive, qualitative methods employed in the semi-structured interviews with agency staff and with families are designed to complement the quantitative components of the evaluation (see Rogowski, et al., 1998, for additional detail on the other evaluation components). The case study interviews complement the other components of the policy evaluation in several ways. They may identify perceptions or experiences that are not possible to analyze with other administrative or survey data. They also may amplify or deepen our understanding of results from the statistical modeling in administrative and survey data. The case studies also provide more immediate feedback on the impact of the program changes than is possible with the analyses of caseloads and costs and other secondary data.

As stated elsewhere in the report, the procedures used to select sites and to sample participant families were designed to provide as much range in perceptions and experiences as possible across the sites visited. While the case studies are based on small samples by design, we implemented a more purposeful sampling procedure (both in selecting sites to visit and in selecting respondents to interview) to ensure variation in the characteristics of the sites and respondents in the final sample. We believe that this variation is important for ensuring that the portrait we obtain of affected families and providers reflects the richest set of experiences and perceptions possible. While some of the outcomes are amenable to summary in quantitative form (e.g., the percentage of families among the total interviewed where a family member reported an increased level of work effort in response to the loss of cash benefits), most results that are presented in the sections that follow are summarized in a more qualitative form. We indicate when a particular outcome was common to the majority of families or occurred for only a few and also describe the range of outcomes raised by families both overall and across the sites. This illustrates which outcomes were more common among interviewed families without suggesting that the interviewed families are a statistically representative sample. The findings describe some of the range in and nature of experiences among families. The results from agency interviews provide a context for the family responses and also contribute a set of questions on policy impact that inform the quantitative analyses.

3. SITE VISIT SUMMARY: LOS ANGELES, CALIFORNIA

3.1 INTRODUCTION

California was selected as a case study site due to a high volume of affected child SSI beneficiaries, high penetration of Medicaid managed care, and demographic characteristics including the presence of urban counties as well as some rural counties with significant child SSI caseloads. We visited Los Angeles, California during the weeks of August 17 and August 24, 1998 and during the weeks of September 6 and October 18, 1999. We interviewed a total of ten families in 1998 and eight families in 1999, in addition to 23 individuals in 14 different agencies.

In 1996, the State of California ranked first among states in the total number of children under age 18 (8.6 million in 1996). In terms of SSI participation in August 1996, California ranked second among states in the total number of children on SSI but ranked much lower in the proportion of children on SSI (ranked 38 at 0.9 percent of children). California ranked seventh among states in the volume of child SSI beneficiaries with IFA (who represented 14.2 percent of the child caseload) and second among states in the volume of child SSI recipients with maladaptive behavior (who represented 6.1 percent of the child caseload).

Los Angeles County ranked highest among counties in California in the total number of child SSI beneficiaries, total IFA and maladaptive cases (3,611), total cases subject to redetermination (5,535), and the total cases ceased with no appeal pending as of January 1998 (1,071). Los Angeles County ranked lower than a number of other counties in the percent completed of those cases subject to redetermination (ranked 15 of 58 counties)—likely due to the size of Los Angeles County's caseload—and in the percent of cases ceased with no appeal pending (ranked 13).

California was not as far along in implementing welfare reform as states such as Michigan and Connecticut. While California had waivers that allowed reforms prior to the 1996 welfare reform law, statewide implementation of California's TANF program began in January 1998. California's welfare program is known as CalWORKs (California Work Opportunity and Responsibility to Kids) and offers transitional child care and transitional Medicaid for longer than 12 months for welfare beneficiaries whose cash assistance is ceased.

California's expanded health insurance to low-income children through the state's Title XXI State Child Health Insurance Program by expanding Medicaid eligibility and by creating a state-only program. Income eligibility for Medicaid was extended to 100 percent of the FPL for children through age 18 years. The new non-Medicaid state program (called Healthy Families) extended coverage for children 1 to 18 years up to 200 percent of the FPL. Cost-sharing for Healthy Families program, which was based on the state employee benefit package and supplemented with vision and dental benefits, was

required only for children with family income above 100 percent of the FPL. Monthly premiums are adjusted by family size and plan type. Managed care arrangements are required for the majority of children enrolled in Medicaid. In most counties (including Los Angeles), child SSI beneficiaries are not required to enroll in prepaid health plans (PHPs).

In the sections that follow, we first discuss the results of our interviews with agency staff at the SSA regional office, the DDS office, and the SSA field office. We then summarize the interviews with Medicaid and other public and private agency staff. Finally, we conclude with a summary of the family interviews in Los Angeles.

3.2 SUMMARIES OF INTERVIEWS WITH SSA OFFICES

3.2.1 SSA Regional Office (Richmond, California)

We interviewed an administrator in the SSA Regional Office in Richmond, California who supervises childhood disability issues for the region. In 1998, the Regional Office had approximately 100 staff, with the Center for Disability having about 12 to 13 program specialists. There is one primary person responsible for policies and procedures, with one person devoting 10 percent time and an assistant working on case control and management information systems (MIS). The region covers four states (Arizona, California, Hawaii, Nevada) and Guam and the North Mariana Islands.

Role in Policy Implementation

The Regional Office has provided support and guidance regarding the processing of claims, claims development, decision-making processes, and support for medical policy and adjudication of cases.

Most of the activities over the past year have focused on clearing up cases from the re-review process. The majority of these cases were denied new applications that had been coded as mental retardation or cessations that occurred under the redetermination process. The administrator we interviewed stated that until early 1999, this was a very labor intensive process because the Regional Office had a significant oversight role as the DDS processed these cases.

The administrator we interviewed noted the effectiveness of the regional cadre process. For deficiencies cited by the Disability Quality Branch (DQB), the regional panel of individuals representing DDS, the regional office, and medical consultant of the DQB reviewed cases to ensure a common understanding of the relevant policy and to ensure that the DQB was correctly citing the specific policy. The regional cadre process also identified those issues that involved unclear policy. This was reported to be an important process within the region because a fair amount of cases had been returned to the DDS offices earlier in the redetermination process. The administrator we interviewed stated that participation of staff from multiple DDS offices contributed to the positive experience with the regional panel process. Because the same people returned at least monthly to

participate in the panel it was possible for participants to develop an appreciation of subtleties in case processing that were developed within the panel and to take the lessons back to each DDS location. The administrator we interviewed stated that this has definitely improved the quality of decisions in California.

Agency Impact and Challenges

The administrator we interviewed noted that while the overall impact of the childhood SSI changes had been significant, staff roles had not changed after the 1996 welfare reform as significantly as they did after the *Zebley* decision.⁶

Staffing and training. In 1998 some of the most significant challenges reported in the interview with Regional Office staff had been ensuring that field offices could identify and handle cases using the correct coding and forms in all cases. These issues were not reported as major problems in the 1999 interview.

Regional Office staff has continued to make site visits to the medical staff in the DDS offices. In late 1999, a speech and language pathologist began working with the Regional Office and DDS offices to help with issues arising with evaluating communication impairments in children. The administrator we interviewed noted that the directive came from the central office in 1998, but it took time to identify an appropriate specialist and to train the individuals in the SSI program and on the speech and language area for children.

Implementation. The administrator we interviewed noted that over the past year, no specific issues came up with quality problems with specific childhood workloads. Because of the way that cases were selected for the re-review, however, some of the problems surfaced more noticeably because they were seen repeatedly. One area that involved the Regional Office was conveying to the disability examiners and the physicians in the DDS offices how the diagnosis of mental retardation and its substantiation as a diagnosis differs from how it is treated under SSA rules. For example, for purposes of SSI eligibility, mental retardation is treated as a marked impairment in cognition while for diagnostic purposes it is defined as an IQ in a particular range. Because much of the re-review was focused on cases that had been coded with mental retardation, these cases were seen often.

When asked about the caseload tracking process, the administrator we interviewed stated that information system challenges have occurred to some degree. The administrator we interviewed pointed out that the nature of the information systems

⁶The February 1990 Supreme Court decision *Sullivan v. Zebley* found that the failure to provide individual assessment of function in children violated the SSI statutes, as did the failure to adequately evaluate children with impairments that were not included in medical listings, or with combinations of impairments that did not fulfill all criteria for any one listed impairment (Rogowski et al 1998, *Sullivan v. Zebley*).

difficulties for different regional offices may vary with the structure of the regional office and how the components work together. In the California Office of Disability, there has been dedicated IS support within the unit handling the childhood SSI issues. The administrator reported that this enabled staff to access the information systems staff directly. When internal reports differed from the reports that were received from the Central Office, it was possible for Regional Office staff to identify the problem directly.

In terms of the data quality, the administrator indicated that there was difficulty getting information about the accuracy rates for the childhood caseload. This was attributed to the slow rate in which information was issued by the Central Office. According to the administrator, the DDS offices wanted to see their accuracy rates and to know how they compared to other offices. The DQB was a source of some information. The administrator we interviewed noted that within the past few months, the quality assurance information had been coming in more consistently.

In terms of Medicaid eligibility for children who lost SSI or whose eligibility continued to be under appeal, the administrator reported that there have been occasional cases where the data exchange information provided to the Medicaid program has been inconsistent. SSI eligibility cessation dates are an area where inconsistencies have occurred. Early on there was significant effort by the SSI team in the Regional Office to ensure that the states received the necessary information. The SSI team also has continued to work on aspects of the Medicaid grandfathering provision. The administrator we interviewed noted that the office within the State of California that performs Medicaid eligibility determinations with non-SSA disability cases is part of the DDS division. Thus any medical eligibility questions relating to the grandfathering provision in California would be handled at that level.

The administrator we interviewed noted several lasting changes that have resulted from the implementation. The childhood coordinator role has become more defined, which facilitates response to childhood issues as they arise. There has been progress in bringing speech and language pathologists into the disability determination process which the administrator felt should have a positive effect on helping the DDS offices work with standardized tests. None of the states in the region has been in a position to handle all of the speech and language issues so having this capability at the regional office has been very important.

The administrator we interviewed also felt that the changes in California's branches that chose specialization had produced some positive outcomes in the months prior to the interview. The administrator noted that the move to specialization had been stimulated by confusion over the welfare reform changes, the re-reviews resulting from the 1997 Commissioner's Report, and experiences with the re-notification process. The administrator felt that the disability examiners and the medical staff appeared to be more satisfied under specialization. The administrator described how the internal structure in California may have worked against the process. The state has 12 branches that have operated fairly autonomously. As a result, there may be only a few pediatricians in each branch, with only a few branches having psychiatric consultants who have worked with

children. The administrator we interviewed also noted that because of the dispersal of the childhood workload among examiners, individual examiners have not had the opportunity to work many child cases so that they can fine tune their skills. A positive change in California over the past few months was that individual branches had decided to begin specializing the childhood cases so that they work solely on the childhood cases. The medical consultants assigned to those units are the pediatricians or the psychiatrists who are familiar with children.

Other branches were reported to be moving in the same direction and were expected to continue to operate in this way given the positive experience to date. The administrator noted that Arizona also has been moving in the direction of specialization and has had positive preliminary findings.

One of the large efforts underway at the time of the interview was the transition to the Prototype model in two offices in California (both in Los Angeles)⁷. The administrator we interviewed noted that this has been a significant process with future impact on the childhood as well as the adult cases. The move toward the single decision-maker and the elimination of the reconsideration step is changing how disability determination will be conducted for the future. The administrator we interviewed did feel that the refresher training and other examples so far had focused on adult cases, with little emphasis or attention to childhood cases. Focusing on how this process is conducted for children (approximately 20 percent of the caseload) was reported as an increasingly important focus for the administrator we interviewed.

The administrator we interviewed noted that there was continuing activity on the part of legal assistance groups with the childhood redetermination process. For example, the San Francisco Bar Association effort had focused attention on providing assistance to parents who were in the redetermination process and then moved into the re-notification process as well. The administrator noted that a number of these cases were being processed at the ALJ level at the time of the interview. As the expertise developed among the volunteer attorneys, they also appeared to become involved with the continuing disability reviews for children.

⁷ The disability Prototype is a redesign of certain elements of the disability determination process. It was implemented on October 1, 1999 in ten states (either statewide or in selected areas). The Prototype design modifies the disability determination procedures for initial disability claims in the State Disability Determination Services (DDS). The Prototype increases the opportunity for claimant interaction and provision of information to the decision-maker prior to an initial decision; provides more decisional authority to the disability examiner and refocuses the medical consultant role on advising, training, and consulting on complex cases; and eliminates the reconsideration step from the appeals process (SSA 1999; Federal Register 1999). The Prototype is under implementation in three of the four States visited in the case studies (California, Louisiana, and Michigan).

Finally, the administrator we interviewed noted that a number of California counties were involved in periodically reviewing their foster care rolls to make appropriate referrals to SSA. Some of the counties were reported to be working with an outside group that provides assistance in the claims process. The administrator also noted that some of the field offices have been very involved with local groups to disseminate information about SSI into the community through normal outreach activities.

Caseload Status

The administrator we interviewed stated that at the time of the 1999 interview, most of the childhood cases that were appealed were pending in OHA. There were a very few cases that had moved on to the Appeals Council level. The administrator noted that firm numbers on these appeals had not been made available for a significant period of time however.

The administrator we interviewed reported that there have been new applications from a significant proportion of the children whose SSI eligibility was ceased in the redetermination process. These new applications, or re-applications, refer to children who were receiving SSI in 1996 and who were filing new applications that are independent of the appeals following re-notification. The administrator estimated that possibly one-third of the children who were ceased in the initial round in 1997 have re-applied. The administrator reported that as these cases occurred, there was attention to whether some of the original cessation determinations could be appropriately re-opened. A number of these applications have been allowances. The administrator stated that the allowance rate on the re-applications was estimated to be in the 40 to 50 percent range. Many of these cases were those identified for re-review. The administrator we interviewed estimated that about two-thirds of the cases that are allowed based on the re-application then are subsequently considered for re-opening. Approximately 20 percent of the re-applications overall have resulted in the re-opening of an earlier decision. According to the administrator, one of the problems with the re-application issue has been that people are so mobile in California that it can be difficult to track the case down within the field office and DDS systems.

The administrator we interviewed did not perceive that there were differences in the new applications for ceased cases, in terms of the original diagnosis relative to the diagnosis in the new application. Most of the cases appear to involve the same diagnoses or allegations of impairment. There may be some subtle changes in diagnosis and changes in how the people around the child are looking at the impairment. Most cases appeared to involve the age range from around 8 to 15 years, not the youngest or oldest children.

There has not appeared to be any change in the volume or the quality of the medical evidence in new applications. The administrator reported that when the applicants have been involved with legal assistance, particularly the San Francisco Bar Association project, SSA does get better information. The administrator stated that the legal assistance organizations understand what kind of information is needed by SSA and are better able to

help the parent pull the necessary information together so that more focused information is provided in the application

Overall, the administrator felt that it was difficult to know how the volume of new applications has been affected by the change in childhood disability criteria. This is in part because of the collateral effects of other provisions of welfare reform and because of changing economic conditions. The administrator estimated that there had been a slight decline in new claims in the post welfare reform period. The Regional Office had estimated in 1998 that childhood applications were down approximately 10 percent from previous years.

Differences Across States

The types of cases seen in the region that includes California were reported to differ in some ways from cases elsewhere in the country. The administrator noted that many of the cases involved children for whom English is a second language, or who live in a non-English speaking home. This has made some of the development issues more difficult.

Some of the larger school districts also have posed challenges in terms of getting the information that SSA would like from the teachers or other paraprofessionals. Getting the child's individualized education plan (IEP) and some of the records that are related to the IEP in the special education office has been possible. However, getting functional information directly from the teacher can be difficult because the school district might not allow it due to liability concerns⁸. The administrator noted that in some cases the teachers may have their own reasons for not cooperating with the process.

In California, there were hearing units that performed reconsiderations of the redeterminations and that moved to different locations due to uneven workloads across the state. The workloads in California did not distribute evenly. In some locations, a higher percentage of children were continued, and this resulted in fewer children at the reconsideration level. In other locations, the ratio was closer to 50 percent continuances. The administrator we interviewed stated that there may be regional differences in how policies are applied, but there also may be differences in the kinds of cases that were on the caseload when the policy change occurred. The administrator we interviewed felt that when the implementation of the welfare reform policies was examined in the region, it was felt that the policy had been applied consistently.

⁸The Education for All Handicapped Children Act (P.L. 94-142) passed in 1975 required that schools develop individualized education plans (IEPs) for children with disabilities; as an education and service plan for the child, the IEP must be developed with parent involvement and based on child assessment (Shonkoff & Meisels, 1990).

The two smaller states in the region—Nevada and Hawaii—have not had many issues come up with the implementation according to the administrator we interviewed. The staff (e.g., disability examiners) has been relatively stable. There have been some difficulties with the mental retardation diagnostic issue and with the cognitive impairments. Little had changed at the state level to the knowledge of the administrator we interviewed. In Arizona, there has been less difficulty in issues of evaluating the cognitive impairments, relative to California. As discussed in the 1998 interview, California does not hire psychologists in the DDS offices (only psychiatrists who generally are specialized in adult psychiatry). Arizona does have psychologists, and this staff has good understanding of childhood issues and dealing with the bilingual issues. Arizona has had more difficulty with physical impairments because they have an older cohort of physicians. According to the administrator, this can present difficulties in the medical consulting staff adjusting to the notion of looking at children's functional limitations outside of the motor area.

In terms of differential impact across population groups, the administrator we interviewed in 1998 indicated that there could be a particular effect on the immigrant population. Even eligible children could be affected if their parents have undocumented status and believe that the Immigration and Naturalization Service (INS) "public charge" provisions could apply to them.¹⁰ The administrator we interviewed speculated that this could affect some parents' proclivity to file new applications, to appeal terminations, and to request benefit continuation during appeal, although there was no specific evidence that this was happening.

3.2.2 SSA Disability Determination Services (DDS), Los Angeles

In 1998 and 1999, we interviewed administrators in case processing and in operations in a Los Angeles DDS office and also interviewed a hearings officer in 1998. There were approximately 125 staff in the DDS office, including professional staff, physicians, and other staff. There were five teams that included a unit manager, two medical consultants, eight analysts, and four to five clerical staff. About 42 professional staff and 30 clerical staff had some involvement with the childhood cases. The DDS office had about eight disability hearing officers (DHOs), out of a total of approximately 32 DHOs in Los Angeles County. By 1999, few changes had occurred to total staffing of the office.

¹⁰ An INS "public charge" refers to a non-citizen who is or who is likely to become primarily dependent on the government for income support on long term care (U.S. Department of Justice, May 25, 1999). Public charge status could conceivably have adverse immigration consequences for the non-citizen as well as financial obligations for the non-citizen's U.S. sponsor (SSA May 26, 1999). Welfare reform and recent immigration laws may cause concern among non-citizens and their families that causes them to forgo public benefits for which they are eligible (U.S. Department of Justice, May 25, 1999). Public charge guidance issued by INS in May 1999 identified income maintenance from TANF, SSI, and State cash assistance as subject to public charge consideration but not SCHIP or Medicaid (with the exception of long term care).

Role in Policy Implementation

The quality assurance section continued to review the childhood cases through 1999. This section reviewed 100 percent of the re-notification and re-review cases. The childhood denials (including initial claims and reconsiderations) and childhood cessations continue to be a focused category in 1999 with review by the quality assurance section.

Most of the childhood caseload had been completed by the 1999 interview, although a few cases of the re-noticed and the re-review cohorts occasionally come through the office. Some are returns from the DQB, but some come from the field offices and have been cases that required substantial development or that were pending specific information from a school, for example.

One of the administrators we interviewed noted that a large number of the reconsideration cessations appeared to have been overturned upon review. For the most part, these were the cases coded with mental retardation, those with borderline IQ, and some cases that involved attention deficit hyperactivity disorder (ADHD). The administrator noted that a significant proportion of the cessations also were overturned by the DHOs in the DDS. There was no specific knowledge at the time of the 1999 interview on the status of cases that had reached the ALJ level on appeal. In terms of new applications from former child SSI recipients, the office had not identified a large volume of new applications from the cohort of children affected by the 1996 law whose eligibility was ceased.

One administrator felt that the childhood cases continued to be the most difficult cases for the office. This was largely because a child might have behavior problems or might not cooperate in answering questions to the extent that the DHOs would like.

According to one administrator, the disability examiners now know that in general, they will need to have information from the school in the form of teacher questionnaires and/or the child's IEP. There is now more contact with schools in developing a child's case. This was reported not to have caused a significant challenge to the DDS, with the exception of the summer months. If the information on a child is not available because the schools are closed, then the case will be held until September when it can be obtained.

Agency Impact and Challenges

Staffing and training. The DDS sent several physicians for the statewide special training in speech and language in 1999. One of the physicians in the quality assurance section received this training. According to one administrator, some but not all of the physicians sent from the DDS to receive this training were psychiatrists. There have been multiple training sessions on speech and language over the past year, in part because these cases have been more difficult to evaluate. All staff received interactive video training (IVT) in speech and language and in several other areas related to childhood cases (mental retardation, borderline IQ, etc.), but the statewide specialized training was targeted to physicians.

Overall, one administrator we interviewed felt that the training received over the course of the post-welfare reform period had been very helpful. This administrator felt that looking at how the children function rather than limiting the evaluation of the child's impairment to the findings from the consultative exams had improved the determination process.

The office has been generalized so all staff members were trained on how to handle the re-notifications and the re-reviews. Some of the other DDS offices have childhood disability specialists, but one administrator we interviewed felt because this branch has relatively few examiners and analysts, it was not feasible to assign the childhood cases to a specialized subgroup of staff. Overall, the childhood redeterminations created a learning experience for office staff, but the administrators we interviewed in 1999 felt that no other lasting changes have been identified.

Implementation. One administrator we interviewed felt that the regional cadre's process of reviewing cases as a group and coming to a consensus on the decision had been useful for the examiners overall. All of the reviewed cases were distributed to the DDS offices rather than only the returns on cases that came from that particular DDS. This administrator felt that the reviews from the cadre generally seemed straightforward and did not appear to be substituting their judgment for the judgment of the initial review. The cadre review process was used within the DDS to assess how the different types of cases should be reviewed.

The CDRs have been coming to the DDS in a relatively steady flow. There had not been any moratoriums on the flow of CDRs. If necessary, the administrators we interviewed noted that it is possible to equalize the caseload across the 2 branches in Los Angeles and potentially across the Southern region if necessary. This had not yet become necessary, however.

The administrators also were asked about families' use of legal assistance and about subpopulations of children affected by welfare reform changes. According to one administrator we interviewed, a relatively small number (possibly 30 percent) of the childhood cases had some type of legal advocate involved at the hearing. No unique issues had arisen with the age 18 redeterminations. A large volume of children in this category had cessations. One administrator noted that overall, it was more difficult for the individuals to qualify for SSI when the adult criteria were applied.

In terms of issues that may have been unique in Los Angeles, the multiplicity in ethnic backgrounds and language in particular was thought by one administrator to have been important. In some cases there would be a need to have an interpreter call the parents if they were going to a CE, for example.

Experiences with Family Response and Impact

One administrator indicated that in most cases when families appeal, they are depending on the SSI for their household income. It was estimated that approximately 80

percent of the payees request benefit continuation during their appeals. The DHO we interviewed in 1998 stated at that time that those parents who did not elect benefit continuation tended to be cases in which the parent believed that the child would not ultimately be found eligible.

At the hearings, most parents appeared to understand what was happening to their child's case, but a few parents have stated that they did not understand the process. One misconception has occurred among some families who have had involvement with family court. These parents sometimes believe that the child should not be brought to the SSA hearing because they are told not to bring the child to the family court proceedings.

The DHO interviewed in 1998 focused on the potential for children's improvement under certain circumstances. The DHO reported that children in child protective services did not appear to have differential outcomes in their cases. Some children in foster care showed significant functional improvement because they had access to special programs. This underscores how child cases are different than adult cases because there often is clear evidence that receiving the SSI benefits has helped the child and family. The DHO described one case in which a twin who had had viral meningitis in infancy and resulting speech delays had received SSI benefits, speech therapy, and preschool education, and had higher functioning than the other twin without any disability.

3.2.3 SSA District Office (Los Angeles)

In 1998, we interviewed a supervisor and a service representative in a Los Angeles County district office. In 1999, we interviewed two administrators in the office. In 1998, the district office had approximately 46 staff, which was down from a total of 80 to 90 staff prior to welfare reform. There were three full-time persons who were brought into the office as a result of the welfare reform eligibility changes. By 1999, the office had lost two claims representatives but was expecting to add a supervisor to the staff shortly.

Role in Policy Implementation

According to the staff we interviewed, the claims representatives who work with initial intake claims are generalists. The claims representatives in the post-entitlement unit also generalize. For the age-18 cases, there is generally one person who handles the forms. The disability unit would handle the case if an appeal was involved.

Over the past year, the staff was reported to have focused on working through the re-reviews and the appeals of the redeterminations. Occasionally, the staff had to reconstruct the case if an individual said that they filed a timely appeal but that their appeal got lost in the shuffle. There has been clerical support for the reconsideration and hearing appeals paperwork, but the generalist claims representatives handle the technical issues.

According to the administrators, the CDRs (including the childhood cases) have significantly increased the workload in the office. In the fall of 1999, the office had been working on a process to streamline the appeals process as part of Prototype (see footnote

7). The redetermination caseload has been unaffected this new process because those cases already were in the pipeline. The administrators noted that while the actual workload has not been a challenge, it had been a challenge to stay current with the CDRs. The flow of the CDRs was halted during the summer. The field office was requested to stop forwarding additional CDRs to the DDS with the exception of the childhood cases. The DDS has continued to accept these cases.

Agency Impact and Challenges

In terms of overall impact, one administrator felt that the staff was accustomed to having different procedures for similar kinds of cases and that as a result the new childhood rules had not caused significant problems within the field office. The administrator felt that the agency had done a good job in getting the new procedures across. The staff knew that it was necessary to explain the process to claimants and understood the steps of the process. The interactive videos allowed staff members to ask questions directly, which helped with this caseload when it initially arrived, as did the on-line guides with the information centralized. Although many of the materials for handling the childhood redeterminations did arrive at the last minute, the administrators we interviewed both felt that the materials did get the key information across.

Overall, the challenges have included the assignment of cases to staff and the need to complete the cases in a timely way. Once the cases arrived and were assigned, and the training had been completed, handling the caseload was relatively routine. There was stress associated with getting through the cases. Also, one administrator noted that the staff members are an older cohort and highly experienced. This had made it difficult to shift the workload when a person was out the office.

Medicaid issues were reported to sometimes come up for claimants. If there was a continuance of benefits with no break, then there is no problem with respect to Medicaid (Medi-Cal) eligibility. The administrators stated that if families do not file in a timely way, however, there can be a break in Medi-Cal due to the SSI cessation. If this occurs, the field office can send a fax to the Medicaid office. One administrator stated that the eligibility system can show a cessation code (in the payment status field) for an individual who has benefit continuation, and the Medi-Cal office workers sometimes don't understand this status. One administrator stated that the caseworkers sometimes talk to the beneficiary and get clarification. The administrator also noted that there is a payment status field in the SSA data system that indicates Goldberg-Kelly status. Medi-Cal offices have access to these data. One of the administrators we interviewed reported having called the Medi-Cal office in some instances to inform them that the individual is entitled to Medicaid. Sometimes the Medicaid office has called to verify eligibility for Medi-Cal with a supervisor in the SSA field office. However, neither of the administrators we interviewed had heard of children whose Medicaid eligibility should have been extended through the grandfathering provision having been terminated.

In terms of permanent changes for the office, one reported change has been the perception on the part of families that claims representatives are performing the roles of

social workers. Another change (though not directly related to welfare reform changes) has to do with explaining the medical development criteria in a rudimentary way to families when they apply. The administrators felt that the claimant conference within the Prototype design would allow more information to be conveyed to the claimant, and that this would allow the claimant another chance to provide any medical information that had not already been provided. This was not a result of welfare reform, but the administrators felt that this would be important for the childhood caseload and that the information provided through this process would make things easier for the field office. One administrator noted that some people believe that they should file an application and that if they go through the appeals process, eventually the judge will overturn denials and approve benefits.

Status of the Caseload

For the most part, the childhood cases if appealed would be in some place in the appeals process. The field office does not track the status of those cases. One supervisor noted that for special caseloads like this, the field office tends to receive statistics on the status of the caseload only if there is a problem list of cases requesting information on their status. The office has not received any of these lists this year so the administrators we interviewed stated they are assuming that the caseload has been moving through smoothly.

The administrators we interviewed perceived that most of the families whose children were affected by welfare reform changes had appealed the cessation. It was felt that most also had requested benefit continuation. A few cases may have made it to the hearing level and a few at the Appeals Council.

A few people did not appeal in a timely way and the only recourse for these families was to file new applications for their child. The administrators stated that usually the claims representatives checked the case status to confirm that there was no way to allow an appeal. If there is no record, then a new application would need to be filed. In a very few cases, the family has an active appeal but is anxious and will call about it.

The administrators reported that the overpayment process is also explained to families. Families understand that they are supposed to routinely submit pay stubs, and unreported income is not waived. There had recently been a refresher training regarding who qualified for waivers. The office may be working on some overpayments due to benefits that were continued during an appeal that ultimately resulted in a cessation. However, the staff has not tracked these cases separately from other overpayment situations. The majority of overpayments have involved unreported income. The overpayments resulting from updated income information can occur when there are backlogs in getting information entered.

One of the supervisors noted that there were established procedures for dedicated accounts that guided staff decisions. The CRs need to apply their judgment in deciding what is good cause. It appeared to one administrator that some CRs were more lenient

while others were more strict. The administrators we interviewed did not feel that there was more lenience necessarily with respect to the childhood cases. The administrators we interviewed also felt that there had been very few requests for waivers that involved amounts sizeable enough to require supervisor review. In terms of dedicated accounts, the administrators indicated that this policy poses challenges to families in establishing the bank accounts. The supervisors felt that the claims representatives do not like getting these accounts. This appears to be in part because it is a process that they need to continue to work on and track, and in part because the dedicated account policy has contributed to families thinking of the claims representatives as "social workers". This has meant a new role for the CRs, who are used to processing the work but not performing this kind of ongoing role. According to one administrator, the CRs also feel that they do not have a good way of knowing whether the funds were spent appropriately. This contributes to higher expectations of the CRs on the part of families. Families have appeared to perceive that the CRs will know all about the family. One administrator noted that the staff is not used to claimants calling to explain how they are going to spend money. Instead the staff members are used to calling the claimants when they need something. One administrator noted that once a family was connected with an agency that was set up to provide a social worker role, the family would get the necessary referrals through that agency rather than expect this role from the SSA staff.

Experiences with Family Response and Impact

One administrator felt that parents either agree with the determination that the child no longer meets the criteria and do not follow through with an appeal or else continue through the appeals process. The administrators did not know how many families might be seeking or receiving legal assistance in the redetermination process.

3.3 SUMMARY OF INTERVIEW WITH MEDICAID AGENCY

In 1998 we interviewed two administrators in the Medicaid program who handled medical and financial eligibility. In 1999 we spoke with an administrator in the Medi-Cal (Medicaid) Program Eligibility Branch of the California Department of Health Services who handles eligibility for individuals losing SSI-linked Medicaid eligibility. The Medi-Cal Program Eligibility Branch is housed in the State Department of Health Services. The new Title XXI State Child Health Insurance Program (SCHIP), called "Healthy Families" in California, is administered by a separate state agency called the Managed Risk Medical Insurance Board.

Role in Policy Implementation

According to the administrators we interviewed in 1998, Medi-Cal had not yet completed the protocols and the necessary programming to handle ongoing eligibility determinations for the grandfathered cohort of children. The protocol was to put children

dropped from SSI into a tracking process. If there is an appeal pending, then the child is maintained on Medicaid through the appeals process.

In terms of the status in 1999, the administrator we interviewed reported that little had changed since 1998 although the children continue to be tracked. According to the administrator we interviewed, there still are plans to do a major system "sweep" for the children affected by welfare reform but because of other priorities, this process had not yet been implemented. The agency continues to have the ability to complete this process using the tapes provided by SSA, when they are prepared to implement it.

The administrator noted that there are screens in the electronic Medi-Cal eligibility files that shows the child's eligibility status linked to Social Security Number (SSN). When they received SSI, the children were in a separate aid category unique to SSI beneficiaries. For the children in the grandfathered group, if the child is found to be in a "share-of-cost" aid category, then the workers are supposed to move the child into a separate aid category that identifies them as medically needy and not receiving cash benefits. A share-of-cost category requires some medical expenditure by the family in the month before the Medicaid benefit can be used. If the child is receiving Medi-Cal but through an aid category that provides full Medicaid coverage with no share-of-cost, then the child's eligibility aid category does not need to be changed. This is because the benefits are the same as would be provided through the SSI-linked aid category. Based on the SSN, these children can still be identified as part of the grandfathered cohort. The administrator we interviewed indicated that there might be some affected children who are still in the SSI-linked eligibility aid category, or who have been moved back to this aid category after having been in the medically needy/no share-of-cost aid category for some period of time. In terms of status during appeal, when a child's eligibility for SSI is under appeal after a redetermination decision to cease benefits, the child can be in the SSI-linked aid category.

Once an appeal is complete (and once the system sweep is implemented), the administrator stated that the plan is to move the children into a new aid category. At this point, the child's eligibility for Medi-Cal would be redetermined based on income and property requirements. Eligibility also would be based on the child's disability status since the individual would need to meet the pre-welfare reform disability criteria. The statewide administrator for the disability aspect of eligibility was reported to be working with the state program that performs disability determinations for Medi-Cal to design the procedure. After this determination is complete, if the child is still eligible then the child would be moved to the new aid category, which provides full Medi-Cal benefits without share-of-cost. Eligibility would then be redetermined annually. The administrator noted that the children are only eligible until age 18 years. At the time the child reaches age 18, they would go through an annual redetermination process and might continue to receive Medi-Cal because they might still be eligible for share-of-cost Medi-Cal.

The administrator we interviewed did not know how many children were at which stage of the appeals process by the time of the 1999 interview. The administrator also was not aware of any figures on children's appeals status.

Agency Impact and Challenges

A challenge reported in 1998 was that the appeals status information provided to Medi-Cal by SSA was several months behind or not updated at all. While Medi-Cal eligibility should continue while the child's case is under appeal, if the appeals status did not get updated, then the Medi-Cal agency would not know the child's level of appeal and would only know that the child was no longer receiving SSI cash benefits. The cash assistance indicator in the information system would tell Medi-Cal that the child should be eligible.

In terms of resource implications for the agency, the administrator we interviewed noted that policies like the grandfathering procedures required significant staff time for implementation. However, one administrator also pointed out in the 1998 and 1999 interviews that the Medi-Cal eligibility issues raised by the SSI changes for children have been much less overwhelming than other changes that are taking place at the same time, such as CalWORKs (California's TANF program) and Healthy Families (California's SCHIP). The reason that little change has occurred is that these other priorities had taken precedence.

Impact on Children's Medicaid Enrollment

The administrators interviewed in 1998 noted that if a child's appeal status was not updated, then the family might need to go through another Medicaid eligibility redetermination process. Due to the Medi-Cal eligibility expansions and also to the TANF recipient status of many families, it was felt that even though some children could have changed eligibility aid categories, they would remain Medi-Cal eligible. The administrator we interviewed in 1999 did not report any additional information on this issue.

3.4 SUMMARIES OF INTERVIEWS WITH OTHER AGENCIES

3.4.1 Los Angeles County Department of Children and Family Services

We interviewed an administrator with responsibility for the SSI section in the Department of Children and Family Services. The Department of Children and Family Services (DCFS) has approximately 5,600 staff positions and a budget of nearly \$1 billion. DCFS operates eight regional offices and contracts with private agencies and foster homes for the care of nearly 50,000 children in out-of-home placements in Los Angeles County.

Roles for Children With Disabilities

The SSI section periodically evaluates whether there have been changes in eligibility for foster care payments, due to the child's income, mental or physical health changes, the child leaving a paid placement, or the child getting married, for example. DCFS also facilitates SSI applications for some children in protective services who are potentially eligible for SSI. DCFS is a representative payee for a number of children in foster care.

arrangements, and as such has responsibilities for responding to the redetermination notices for children in foster care receiving SSI and any other requests for financial or medical documentation received from SSA. According to the administrator we interviewed in 1998, DCFS has sought to obtain SSI benefits for eligible children in out-of-home placements so that they have this income as an ongoing resource once they leave their foster arrangements.

The administrator we interviewed in 1999 indicated that over the past six months prior to the interview, DCFS had made some operational changes in its activities as a representative payee. Representative payee cases for DCFS have generally been handled through one field office in the Los Angeles area. The administrator we interviewed in 1999 felt that these recent operational changes have been helpful to and appreciated by the SSA office. The administrator we interviewed noted that there is a good, cooperative relationship between DCFS as a representative payee and the SSA field office that handles most of the cases for children in protective custody.

Response and Observations of the Policy Impact

According to the administrator we interviewed in 1999, DCFS makes the decision about whether or not to appeal a cessation of SSI benefits for a child, as the representative payee. The case-by-case decision is based on a professional judgment about the child's current health status and functioning. One example is a child in foster care who was born drug-addicted. After reaching five or six months of age, the child can be doing better developmentally, and thus may no longer meet SSI disability criteria. In other instances, a child may be having continued problems in functioning with DCFS having to provide additional foster care funds (e.g., higher payment rates for the placement based on physical or emotional functioning). Dedicated accounts established for children in protective custody have been an issue for the Department. The Department is not able to use these funds for foster care expenses. However, it is possible for the funds to be used for computer equipment or extended orthodontia for the child, for example. According to the administrator we interviewed in 1999, the process has been to inform the SSA field office in advance of purchases or expenditures that are planned for the dedicated account funds. Then a foster parent can make the purchase and get reimbursed or alternatively can get an estimate and submit the estimate to DCFS.

More generally, the administrator we interviewed noted that there was a need for county departments to work closely with SSA to ensure that children are receiving benefits for which they are eligible. The administrator noted the particular needs of children reaching age 18 because of all of the transition issues around emancipation. Once a child is reaching emancipation age, a child welfare department can apply for SSI for the child. The child welfare agency could continue to receive federal Social Security Act Title IV-E foster care payments (see footnote 1) on behalf of the child by not accepting the SSI payment for up to 12 months, but the administrator we interviewed felt that an extension of this period would be helpful.

The administrator we interviewed stated that gathering the necessary medical evidence to support a child's SSI application or appeal was a continuing challenge. The child welfare caseworkers are one source for this information, but often it is necessary to get information from the caregiver. The agency now has more proactive procedures in place to try to solicit this information. These procedures include a trigger to follow up within 10 days with the caregiver, and a phone call to explain the need for following through. In some cases, the administrator noted that a foster parent will admit having discarded the original information request.

3.5 SUMMARY OF FAMILY INTERVIEWS

We interviewed ten families in the Los Angeles area during the weeks of August 17 and August 24, 1998. The child SSI beneficiaries in these families were reported by the interviewed parent(s) as having the following types of medical conditions when they began receiving SSI: mental retardation/learning disability; seizures and learning disability; mental retardation; emotional disorder; emotional disorder and learning disability; learning disability; hearing loss; cardiac condition; attention deficit hyperactivity disorder (ADHD); and learning disability¹¹.

We conducted follow-up interviews with seven of these ten families in 1999 (and a partial interview with an eighth family). All were conducted during the week of September 6, 1999 with the exception of one interview conducted in November 1999.

3.5.1 Experiences with the Redetermination Process

Outcome of the Redetermination Process

In 1998, eight of the ten families reported that they had appealed the termination of SSI benefits either at the initial termination or later in the process. One of the ten families completed a new application due to missing the appeal deadline, and one never appealed.

In 1999, two of the eight families who were successfully re-contacted and re-interviewed reported that the child was currently eligible and receiving SSI benefits. Three of the families reported that the child had been terminated from SSI with no appeal pending (two other families not re-interviewed in 1999 reported this outcome in 1998). Two families interviewed in 1999 stated that the child's SSI was still pending an ongoing appeals process (one other family not re-interviewed in 1999 reported this outcome in 1998).

¹¹Caretakers were asked in the interview about medical conditions that led to the child's initial eligibility for SSI; these conditions are self-reported with no attempt made to compare the information with SSA administrative records.

Understanding of the Redetermination Process

Several parents expressed confusion with the appeals process at the follow-up interview in 1999. One parent reported not having received any information on the status of the child's appeal in over a year and did not understand why nothing had been received. One parent reported feeling that there was some disorganization in the way the child's appeal and eligibility determination were handled. The parent reported this perception in part because after responding to the 1998 "good news" letter in what was felt to be a timely way, the field office stated that their time window was exceeded for an appeal.

In 1999, several parents provided explanations for why they had missed a scheduled appointment or had not responded in some other way. One parent reported having missed a recent hearing because the child's grandmother was in the hospital. This parent believed that she could write to explain why the appointment was missed and to reschedule. Another parent stated that he had appealed the child's termination after the "good news" letter, but missed an appointment for the child (who turned 18 in 1999) because the parent was hospitalized at the time. This parent reported having lost the letter with the child's appointment information. The parent reported that the local SSA office did not give him another appointment or a number to call, and that he was told that he could not reschedule or re-apply for the child. Three other parents stated that they were expecting to hear something from SSA about a pending appeal or a request that they had submitted, but that they had not followed up with the local office to check on the status of the appeal or request. One of these parents stated that she had called an 800 number so that she could receive benefits during the appeal, and said she was told to wait because SSA would call her about it. This parent stated that she had not heard anything or followed up herself with the local field office.

Appeals and Benefit Continuation Requests

In 1999, SSI eligibility had been restored to one parent who reported in 1998 having not appealed the child's cessation (with benefits ceased in early 1998). This parent interpreted the explanation from the local office in 1999 as the termination having been a "mistake".

In 1998, of the eight families who appealed, five reported that they had requested benefit continuation. Two of these five families were continuing to receive benefits at the time of the 1998 interview.

Of the families who received benefit continuation during the appeal, two reported in the 1999 interview that an earlier cessation was affirmed on appeal and that they were required to pay back the overpayments incurred during the appeal. One of these families was still receiving benefits during the 1998 interview, while benefits to the child in the second family had already stopped. Neither family had requested a waiver of the overpayment, or stated that a waiver was an option for them. One of these families reported that they were making monthly payments to SSA, and the other parent had only recently been notified of the appeal status and thus had not made arrangements for or

begun the repayment process. The parent reported being told in 1998 that she would definitely have to pay back the full amount and did not believe that she had any alternative. The other parent said she had been told there was a "50/50" chance that she would lose the appeal and have to pay back the benefits received during the appeal.

In 1999, SSI eligibility was restored to one of the three families who appealed and did not request benefit continuation. For this family, a dedicated account was set up because benefits had not been received for over a year. According to the parent, this account was no longer being handled as a dedicated account, however. The parent indicated that an initial payment was made to the account, with additional payments expected over a period of time. The parent reported having notified the SSA field office shortly after the account was established because of a decline in working hours, and the parent reported that the field office allowed the family access to all of the funds. These funds were used for rent and for necessary items for the child (e.g., clothing, a bed).

3.5.2 Impact on Medicaid and Health Care Access

Medicaid Eligibility and Enrollment

In 1998, two families reported that Medicaid eligibility had been terminated for the child. Of these children, one was a child who turned 18 in 1998 and whose case was first appealed in that year; this child had lost Medicaid coverage after turning 18. The second child lost Medicaid coverage after SSI benefits were ceased, but regained Medicaid coverage when the child began receiving AFDC/TANF benefits about one year later.

Several parents expressed concern in 1998 that their children's Medicaid coverage would be terminated once their appeals were decided, although they did not have specific information one way or the other.

In the 1999 interviews, Medicaid had not been restored for the child who had turned 18 years of age; the parent of this child specifically stated that because they did not want to get involved in the welfare system, they would not go to the welfare office to see whether there might be another way of qualifying for Medicaid. A follow-up interview was not conducted for the other family whose child had lost Medicaid. For all other children whose families were interviewed in 1999, Medicaid eligibility had continued, and none of the parents reported receiving letters or any indication that the Medicaid might stop.

Transitions to Prepaid Health Plans

In 1998, parents of five of the nine children who were still enrolled in Medicaid reported that their child was enrolled in a Medicaid prepaid health plan (PHP). Two of these five parents said that they had to enroll their children in PHPs when the SSI benefits stopped. Children of the other three parents were already enrolled in a Medicaid PHP prior to welfare reform. In 1999, there was no additional enrollment in PHPs of the

children who were not in PHPs in 1998, and no additional reports from parents believing that they were required, or would in future be required, to enroll the child in a PHP.

Use of Private Health Insurance/SCHIP

As of the 1999 follow-up interviews, none of the children had been newly enrolled in private employer-based health insurance or in the State Child Health Insurance Program in California ("Healthy Families").

Use of Legal Assistance

Two parents reported in 1999 that they had sought legal assistance. One of these parents stated that she went to see a lawyer and was told that they would not become involved at that time but to come back if the next appeal affirmed the earlier cessation. The benefits were later restored for this child, and thus the parent had no further contact with legal assistance. The other parent stated that she had called a legal aid office for assistance but that the call had not been returned. None of the families reported seeking legal assistance and being denied help.

Several parents explained why they had not sought legal assistance at any point. One parent stated that she did not get a lawyer because of the expense. Another parent stated that she considered getting legal help, and called a lawyer that a friend had recommended to check on the cost. The parent reported being told that it would be \$600 to have a discussion about the child's case and thus decided not to pursue legal assistance.

Another parent whose child's SSI benefits had been ceased, but whose health status had since worsened in the eyes of the parent, stated that if the family decided to reapply for SSI for the child, they might get a lawyer involved from the beginning.

Access to Medical and Mental Health Services

In the 1998 and 1999 interviews, several parents reported issues of access to health care that were unrelated to the changes to SSI. In 1998, one parent felt that the referral requirement imposed by enrollment in a Medicaid PHP was making it difficult to find a specialist to help with her child's mental health problems. In 1999, one parent stated that Medi-Cal covers exams but not lenses and frames, and thus the child did not yet have glasses although the parent felt that they were needed. Another parent felt that her child (covered by Medicaid fee-for-service) needed psychiatric help and was referred to a psychiatrist by her child's pediatrician, but reported that the psychiatrist's office had "started talking about money right away" and felt that she couldn't afford it, and the child did not receive any services. Another parent stated that her child was not receiving speech therapy because school staff only came to get the children who were in special education and did not remember to get her child, who was in a regular classroom, from his class.

3.5.3 Socioeconomic Impact

Total Income Levels

In 1998, income levels had not changed for the two families who requested benefit continuation and continued to receive SSI benefits during the appeal. Of the remaining families—all of whom were no longer receiving SSI benefits—total family income had increased for the three parents who began working or increased their working hours after losing the SSI benefits. Family income had declined for the other five families who were not receiving continued SSI benefits.

By 1999, income was reported to be higher (relative to the first notification of an SSI eligibility change) for two families. These two families both had had their child's eligibility for SSI restored and were receiving monthly benefits; total income had increased due to entry into the workforce or due to increased work hours. Income was reported to be higher for a third family in 1998 but no follow-up interview could be conducted in 1999.

In contrast, income was lower in 1999 for five families (and was reported as lower in 1998 for an additional family that was not interviewed in 1999). Two families who had lower income in 1999 did report that their income had increased somewhat between 1998 and 1999 although they had not fully made up for the loss of SSI income.

None of the families had a similar income in 1999 as they had just prior to notification of the SSI eligibility change.

One of the families reported having submitted a new application for child support in 1999. This parent said she had been told that it could be 3 or 4 years before she received any child support. None of the families reported receiving child support in the 1999 interview and with the exception of this one family, none reported having ever submitted applications for child support at any time.

Work Participation

In three of the ten families, the parent was working at the time that the SSI eligibility change occurred. About half of the non-working parents were not in the workforce due to disability. Two parents were receiving disability income for themselves; one was receiving SSI, and one was receiving Social Security benefits. One parent was receiving unemployment. In the four remaining families, the parent was not working.

Of the three working families, one increased working hours following the loss of SSI benefits. Of the five families, in which the parent was not working at the time that SSI benefits were lost (and was not disabled or elderly), two families subsequently entered the workforce. The parent in one of these families had been only temporarily out of the workforce. Thus in 1998, a total of three families reported having increased their working hours or having a new job since the change in SSI eligibility. In the remaining three

families, the parent had not yet entered the workforce and remained completely dependent on public assistance.

In the 1999 interviews, a total of five families stated that they had increased their working hours or taken an additional job since the SSI change occurred.

Use of Public Assistance

A total of three parents stated in 1998 that they had applied for or intended to apply for cash assistance to replace the lost income. One parent had added the child who lost SSI to her AFDC/TANF cash grant, and stated that it had taken a year to get the child added to the cash grant. The second parent was able to add the child to this cash grant immediately. Follow-up interviews could not be conducted for either of these families in 1999.

Another parent who was not receiving public aid (other than the SSI) in 1998 stated that she planned to apply for AFDC/TANF for the child who had lost SSI. By 1999, the child had not been added to the cash grant, however, because the child's SSI eligibility was restored.

None of the families interviewed in 1999 reported any other efforts to seek public aid, and receipt of public aid had not changed (ceased or declined) for any of those who had been receiving public aid when SSI eligibility changed. In the 1999 interviews, none of the families who were receiving public cash assistance stated that they expected that their public aid benefits might stop at some point, or stated that they had heard about TANF work requirements or other benefit restrictions

3.5.4 Caregiving and Other Child Impact

Living Arrangements

In 1998, four of the ten parents had moved or changed living arrangements since the SSI change. One of the parents who moved attributed the move (to a boyfriend's house) to the income loss. The other families who moved did not attribute their moves solely to the loss of SSI.

No additional moves or changes in household composition were reported by families in the 1999 interviews (one parent did get married between the 1998 and 1999 interviews). However, residential status could not be confirmed for the two families who could not be contacted in 1999.

Child Care

None of the parents we interviewed in 1998 reported currently using or ever using non-kinship child care. In 1999, none of the parents identified child care arrangements as

a problem because they had been able to work out job hours that did not create significant child care challenges.

Other Child Impact

Many of the parents reported concerns about their child's health and functional status in both the 1998 and 1999 interviews. However, none attributed these concerns specifically to the loss of SSI income. Two parents reported that their child's health status had declined by 1999, and one of these parents felt that the child now qualified again for SSI even under the new eligibility criteria.

4. SITE VISIT SUMMARY: FRESNO, CALIFORNIA

4.1 INTRODUCTION

As discussed in Section 3, California was selected as a case study site due to its high volume of affected child SSI beneficiaries, its high penetration of Medicaid managed care, and its demographic characteristics including the presence of urban counties as well as some rural counties with significant child SSI caseloads. We visited Fresno County, California during the week of October 26, 1998 and during the week of October 25, 1999. We interviewed a total of nine families in addition to 14 individuals in six different agencies in 1998, and a total of eight families in addition to 16 individuals in 6 agencies in 1999.

Fresno County ranked sixth among counties in California in the total number of child SSI beneficiaries. Fresno ranked third in total IFA and maladaptive behavior cases, third in the total cases subject to redetermination (1,157), and second in the total cases ceased with no appeal pending as of January 1998 (305). Fresno County had the highest ranking among California counties of the percent of the under 18 child population receiving SSI (1.6 percent) and in the percent of child SSI beneficiaries with IFA and/or maladaptive behavior (22.2 percent).

Because the SSA Regional Office as well as the programs and policies in the California State Department of Health and Department of Social Services apply both to Los Angeles and Fresno counties, the summaries of those interviews provided in Section 3 are not repeated in this section. Thus, in the sections that follow, we first provide a summary of interviews with staff in the DDS office and the SSA field office. Next are summaries of interviews with other local public and private agency staff, and finally the summary of the family interviews in Fresno.

4.2 SUMMARIES OF INTERVIEWS WITH SSA OFFICES

4.2.1 Disability Evaluation Division, California Department of Social Services

We spoke with two examiners, an operations specialist, and an administrator of the Disability Evaluation Division (DED). The DED has six teams with seven to nine analysts per team. In total there are about 50 full time equivalent (FTE) staff working on disability evaluations.

Role in the Policy Implementation

Over the past year, the staff we interviewed indicated that most of the activity had focused on the CDRs. There have been a small number of re-review cases over the past

year (as well as a few *Zebley* cases). The total childhood caseload (including CDRs, both initial and reconsiderations) had not changed significantly and was reported as representing about 15 percent of the total caseload.

A major activity in 1998 was compiling the policies and procedures necessary to guide the staff through the redetermination process. Staff interviewed in 1998 indicated that the information in the emergency transmittals on redetermination procedures often was not structured to fit within the existing manual, and that there was little time for integration because the policies and procedures needed to be implemented immediately. In 1998, the staff we interviewed noted that it was helpful to get the information quickly, but that it took significant staff time to make changes throughout the manual so that the procedures could be followed. By 1999, the compilation of policies and procedures was no longer a significant issue for the childhood caseload.

Impact on the Agency

The staff interviewed in 1999 reported that the office had created a school "help desk" so that if staff are having difficulty getting necessary information from the teachers, or the speech therapists, the person who works on the help desk issues can take this on. Schools have been very important but also very challenging in terms of getting the necessary information. This is because of the scope of the information (length and number of questions) that is requested. One staff member also felt that personal opinions can get in the way of getting the forms completed. For example, this can happen around the issue of whether a speech and language problem is characterized as a disability. The office is trying to solicit an objective opinion, but the school staff can be hesitant to present the problem as a disability because it can label a child. This may stem from the fact that the schools are trying to bring children to full functioning and want to work on rehabilitation and therapy rather than "label" a child.

The professional liaison specialist has contacted several school districts to do presentations to some of the administrators, hoping that a better response on teacher questionnaires could be an outcome. It appears that the message has not gotten to the full school district staff, so the DDS staff plans to return to talk directly with the teachers. The DDS staff we interviewed noted that there is a logistical issue involved with getting the teachers to come in together on their own time for the training. Another issue reported by the staff we interviewed was that the schools do not view themselves as providers of medical evidence and feel that their role is to teach children rather than to document disability. Thus there is an institutional role issue. Moreover, there are multiple levels within the schools (e.g., administrators, teachers). Another issue relating to procuring information from the teachers stems from the large farm-working population in the area. Because children often change schools, the teacher may not feel sufficiently knowledgeable about a child to complete the teacher questionnaire.

The staff we interviewed did not feel that gathering medical evidence for children posed specific challenges that did not occur for adults. In general, in terms of issues in gathering medical information overall, children have tended to go to clinics more than

adults do. One local hospital medical records department has tended not to be very responsive to DDS requests. One DDS staff member we interviewed noted that social workers at the hospital are quite adept at getting the necessary information together in a timely way, however.

One staff member noted that medical evidence in general has been more difficult to obtain. The consultative exam rate was reported to have increased from 48 to 52 percent in the office. The staff we interviewed indicated that there are both positive and negative aspects of the CE process. The staff pointed out that the welfare reform law placed significant emphasis on the treating physician as a source of medical information for SSI disability determinations. On the other hand, this emphasis has come at a time of managed care where families might face barriers to accessing specialty physicians. It is possible that this could affect the medical information available in childhood applications in the future. There also are many people without health insurance although the staff we interviewed noted that children may be more advantaged than adults in terms of having access to health insurance.

Staffing and training Few changes in organization or staffing took place in the office between 1998 and 1999. The office has continued to be generalized with no specialization in childhood cases.

The staff we interviewed reported that they knew more about the determination of childhood eligibility in 1999 than they had in 1998. One staff member noted that a recent figure on accuracy was 92 percent (on denials) whereas this figure had been in the mid-80s for other caseloads. The staff attributed this improvement to clearer instructions and definitions of categories, and also to a growing familiarity with the process. While the multitude of categories for the childhood cases has continued, the volume had declined as well. One staff member noted that the childhood cases continue to be a challenge because the cases are so individualized. The staff member reported that this is not just due to the re-review tracking issues but instead is due to the way the cases are evaluated.

There has been a continued evolution of the medical evaluation. Over the past year, the largest emphasis has been with speech and language, in terms of trying to determine what constitutes a disability under speech and language. The office has two medical consultants who serve as the speech and language experts. The staff we interviewed stated that the office had found that it was not possible to bring on a speech and language specialist. The office was successful in finding some specialists who could come to train staff on speech and language. The professional relations specialist has been a key person for this. The staff we interviewed reported that a training program was developed and that the specialist presented this material to the DDS staff who were serving as the speech and language experts. This was done for the office but then went to a statewide application.

The specialist also worked with the professional relations specialist on a form that the office can send out to the schools or to speech therapists so that the office can get the information that it needs.

Implementation. In 1998, some of the challenges reported by the staff we interviewed had to do with getting an adequate volume of physicians for children's consultative exams (CEs), and also receiving the caseload as expected. This was no longer an acute problem in 1999. In terms of how the process could have been improved, one staff member noted that getting enough information before the caseload arrived would be critical. This was a concern initially and still continues to be on some level. If SSA provides information to all offices through interactive video training (IVT) prior to the start of a program or caseload, there would not be the need to re-do the cases even if it is only to recode the cases. An examiner noted that without detailed information from SSA, the examiners have some difficulty knowing exactly what it is that SSA really wanted. The IVT sometimes comes just a day before the policy becomes effective, and many questions are raised that the next iteration of the IVT then addresses. The staff is supposed to begin using the new instruction with little written documentation and with a significant number of outstanding questions. One staff member felt that there has not been sufficient recognition of the operational impact of this roll-out approach. Moreover, the cases then move to the DQB where more interpretation can occur that then stimulates another round of changes. One administrator we interviewed noted the importance of the policy branch considering the impact of the change, getting the regulations out in a timely way, and ensuring that the training mechanisms are in place. The staff we interviewed noted that the reason that the 1996 changes exacerbated this problem of timeliness is that there is so much more to look at in the childhood cases.

One staff member noted that because the welfare reform changes involved a curtailment of benefits, SSA kept asking the office to look at cases more carefully. This staff member felt that the cadre reviews have not been resulting in changes in allowance or denial but instead in very careful documentation. One examiner noted that there was a large burden from procedural issues. One effect was that the examiners had to continue waiting for a teacher questionnaire or that an examiner was continuing to put more effort into a particular aspect of the case development. The cases may come back with a statement that a further follow-up phone call should have been made, for example. According to the examiner we interviewed, the return might not provide a rationale. Instead, the return would indicate that the case had been evaluated appropriately, but that a specific element of information would have been important for the particular case. One administrator noted that they make every effort to get all of the information for the childhood cases, but find it difficult to have the cases reviewed in such an individualized way. One staff member indicated that in these instances, the review may not serve to fine-tune the process but instead usurp the original process. An example was offered of a parent whose child's case was being re-reviewed. No appeal had been filed and the parent was clearly competent to represent the child and offered good reason for not wanting to appeal. This case was sent back multiple times because the parent did not take the child to a CE.

One administrator noted that the childhood cadres that were the source of these returned cases were supposed to convene with all the latest knowledge about the childhood cases. A staff member from the DDS had participated in this process, which was designed to make sure that cases referred back from the DQB were not

inappropriately "reaching" or "stretching". These cadres reviewed the cases to ensure that the regulations were being interpreted consistently and that there was agreement on the interpretation. Several staff members we interviewed perceived that in some cases, this process tended to create the kind of thinking where it appeared that the cadre was continually seeking out whether anything more could have been done. The potential problem with this process is that it gets very detailed. One staff member suggested that the different cadre groups might have had different perspectives on what met the regulations. The failure to cooperate cases were particularly subject to this problem, according to this staff member. A review might conclude that the regulations had been met, but that more should have been done. The feedback from the cadre was then incorporated into local policies for childhood cases. In terms of the end result, one staff member noted that some examiners may feel that they are spending too much time on some of these issues.

One staff member felt that once the changes were made, the decisions in the reviews and re-reviews were more than fair. Another staff member felt that the process takes longer but the decisions are better, even though there was always effort in the past to make the right decision.

Another staff member pointed out that there always is a tension between what SSA can fund and what it would like in terms of the determination process. One staff member noted that being able to provide the necessary, regular training on an ongoing basis and ensuring that staff is prepared for upcoming changes makes a significant difference in implementation. The program is complex and shifts over time. As a result in some cases the offices have to almost force the instructions out of the policy office. According to some of the staff we interviewed, the regional office has provided more guidance while the central office is providing more information in the form of guides, in addition to the directive. Having this in combination with the training was perceived by one administrator as the direction that SSA needed to follow.

Caseload Status

There was a moratorium on the CDRs during the summer due to the large volume. Ideally the CDRs would flow evenly throughout the year. A pattern that may continue to happen is that the case numbers are supplied to the field office to identify the next round of CDRs (via diaries). These cases are developed over a period of time, but the workload comes all at once to the DDS.

The staff members we talked with had not observed a significant volume of re-applications for children whose SSI was ceased pursuant to welfare reform. One staff member noted that with children, the DDS does not see many cases that are filed and then re-filed several years later. The staff members we interviewed generally felt that once the children were taken off the SSI rolls, they were tending to stay off. (A staff member also noted that the office had not had a very large workload of re-noticed cases either.)

Several staff members we interviewed also felt that they might not identify re-applications as such in all cases. One staff member noted that sometimes the field offices put the new applications in new folders without providing much history about a prior status. Prior file recovery was pointed to as a significant issue that has become more significant with the CDR process. The DDS does get cases back from the DQB on childhood cases where a previous decision was missed, for example.

4.2.2 SSA District Office, Fresno, California

We interviewed two supervisors and two claims representatives in 1998 and in 1999 in a district office in Fresno, California. The district office had about 22 claims representatives in 1998 and 18 in 1999 in addition to two supervisors. One supervisor was responsible for initial claims and CDRs, and redeterminations are handled by the second supervisor. The office no longer has specialized claims representatives so all claims representatives (CRs) have handled both SSI post-entitlement and special claims.

Role in Policy Implementation

While a number of the challenges reported in 1998 focused on contacting and communicating with families, by 1999 the challenges appeared to focus on ongoing post-entitlement eligibility issues. The staff we interviewed in 1999 noted that there had been an increasing volume of wage alerts. One CR noted that one parent recently had 6 different employers who needed to be tracked down. In the quarterly income review, the number of working families as well as the number of employers for these families had increased. The CRs noted that the volume combined with increased use of computers posed a significant workload for the office. The CRs observed that computerizing all of the records would save time in the long run but at the time of the interview was requiring significant work in contacting all families.

In terms of the benefit continuation and overpayment issues, the supervisors we interviewed felt that there was a large volume of appeals for the childhood cases. The policy for repayment has been that if the parent asked for payment continuation and cooperated with the appeals process, then the overpayment could be waived. However, if a parent did not cooperate during the appeal by attending hearings, for example then the parents have been asked to re-pay the overpayment. The supervisors we interviewed felt that this was a clear and straightforward policy. The 1999 findings regarding overpayments that resulted from appeals were consistent with the findings from 1998. In the initial interview, the CRs we interviewed felt it did not make sense to require families to use public assistance payments (i.e., AFDC/TANF) to repay past public assistance payments (i.e., SSI). At that time, the CRs reported that few parents were being required to or were repaying the overpayments.

With respect to Medicaid eligibility, the CRs reported that the Medi-Cal program had a policy to continue eligibility for the affected children under age 18. One of the supervisors explained that sometimes the SSA office received a request for the status of an

individual. The supervisor had the lists and was able to provide these lists to the county welfare office so that the county would know at what point they should take over the Medi-Cal coverage. The supervisors we interviewed noted that the families received notices about the child's Medi-Cal status. Field office staff also have explained to the families about the county program so that the family could take care of any problems relating to the Medicaid status of the child. The staff we interviewed reported that there has been little activity around clarification of children's Medicaid status. There had not been a significant role for the office or a significant volume of complaints to the SSA field office from families regarding Medicaid eligibility.

The CRs felt that there they had not heard from families about many Medicaid problems because Medicaid eligibility is handled by the county. One CR noted that adults have occasionally complained about Medi-Cal coverage of certain medications but that such issues rarely have been raised for children. The CRs also stated that they provide information to families about the Healthy Families program in case a child no longer qualifies for Medicaid.

Agency Impact and Challenges

Staffing and training. In the 1998 interviews, the staff members we interviewed noted that all staff had to be trained on childhood SSI issues when the welfare reform policy changes occurred. This was because the office used a generalist model. The staff observed that specialization had been necessary prior to the welfare reform law when the workload was very high and before the computer programs were available. By 1999, the claims representatives that we interviewed noted that although they were technically generalists, the CRs are in some ways "specialists" in different areas. It was reported that the CRs go to each other for guidance on specific topics in SSI eligibility such as eligibility issues for the immigrant alien caseload, for example. Having one person with a very detailed understanding of overpayments or of alien caseload issues was reported by those we interviewed to allow the CRs to feel more confident about their work while maintaining the generalist approach. The CRs noted that the on-line guidance also has been very helpful as a reference.

The CRs noted that the office had lost two of the Spanish-speaking CRs and that this had left the office with only two Spanish speaking CRs. According to the staff we interviewed, the CRs ask families to have someone there whenever possible who can interpret when there is telephone communication between the family and the field office staff.

Implementation. Because the SSI program has been identified as a high risk program, the supervisors we interviewed indicated that there has been more micro-management and formal accountability at the same time that the childhood changes took effect.

The supervisors felt that they generally had been able to keep up with the childhood caseload. The DDS was thought to be more overwhelmed than the field office with this

caseload. The supervisors we interviewed reported that the good relationship between the field office and the DDS had helped with caseload issues. According to the staff, the field office and DDS worked out an arrangement for the age-18 and regular childhood CDRs so that the field office would not have to update those cases that had waited at the DDS longer than 30 days.

Dedicated accounts. A significant problem for the claims representatives and for the office overall has been the dedicated accounts. In 1998, several staff members noted that problems could occur at the field office level when new policies were not fully reviewed for their operational consequences at the local level prior to dissemination. In 1999, staff re-emphasized this point and noted that the dedicated accounts have presented a public relations problem for the field office because the families are being told how to use these funds with no repercussions if the family does not use the funds as instructed. The staff we interviewed observed that the families are required to account for the money that is spent in an annual report, but they may never have had bank accounts and had to manage money over this period of time. The staff members we interviewed felt that there were no real consequences for the parent if the dedicated account funds were misapplied. Even though there have been few repercussions for the families, the CRs have still been required to work through the development of any misapplication.

This was perceived by one of the supervisors as an ongoing "power struggle". One supervisor reported that allowable use of dedicated account funds has been somewhat vague and that approval can vary from office to another. Because the law has few consequences and lacks some clarity, the staff we interviewed felt that it has been particularly vulnerable to difficulties. One supervisor noted that cultural issues have emerged such as whether the money can be used for services of a shaman. In this example, the field office had consulted the regional office for interpretation of appropriate use. The supervisor noted that another office or individual might not make this effort at clarifying what met the guidelines. One CR noted that if there was public transportation available, a car or car repairs might not be allowed as a dedicated account expenditure but felt that this was not sensible for a family whose child had a disability.

By 1999, the CRs reported that the volume of dedicated accounts had declined over the past year. Fewer children were being continued after an earlier cessation or were being allowed at the initial claim level. The CRs observed that if the staff member who explains the dedicated account to the family emphasizes the limits on how the money should be spent, the family will ask questions before spending the money. The CRs both felt that very clear explanations were needed with clear verbal and written information. Otherwise the parents were more likely to spend the money and say that they were never told about the appropriate uses. One CR noted that if dedicated accounts for children were set up like those for adults, with small incremental payments, the same kinds of problems would not have arisen. The CRs were beginning the first round of annual reviews for children's dedicated accounts at the time of the 1999 interviews.

Caseload Status

The CRs felt that most appeals of childhood cases have reached the ALJ level. Neither of the CRs we interviewed knew of many cases that had been approved at the ALJ level. In terms of decision about appeals, one CR felt that the two-parent working families were less likely to continue to appeal after cessation decisions. The staff reported that they have seen some re-applications for children whose benefits had been ceased based on welfare reform changes. The CRs felt that these re-applications were generally due to worsened health status of the child or due to a new disability. The CRs also noted that it may be due to a teacher or a physician encouraging the parent to return to SSA. One CR further stated that some teachers and physicians appear not to realize that SSI is a means tested program and that they have continued to refer families who do not meet the resource limits.

Experiences With Family Response and Impact

The supervisors we interviewed felt that after the initial shock of the implementation, families appeared to understand the redetermination process. This may be partly because the CRs clearly explained the new rules and outlined the redetermination process to families. Families appeared to be expecting the CDRs as well and to be aware that continuing reviews would be occur periodically.

In terms of particular families that might be affected, the CRs we interviewed felt that the work requirements of welfare had not yet affected the families very much. The acculturation of parents and their entry to the workforce appeared to be having independent effects on some families' declining reliance on public assistance.

4.3 SUMMARIES OF INTERVIEWS WITH OTHER AGENCIES

4.3.1 Fresno County Department of Social Services

We interviewed an eligibility worker in the Department of Social Services who is a member of a recently formed advocacy program on SSI. This advocacy program had been created in 1999 not because of welfare reform changes to SSI eligibility, but for adults and children in General Relief and CalWORKs programs before time limit took effect.¹²

Roles for Children With Disabilities

The staff member we interviewed stated that referrals that have been made to the program so far have come largely from the CalWORKs and General Relief populations. A referral can be triggered if the parent tells the eligibility worker in a welfare office that a

¹² General Relief is a program operated by California counties that provides income assistance for certain low-income individuals who do not qualify for AFDC/TANF benefits.

child's health problem causes the parent to be unable to work. The eligibility worker then can refer the family to the new program. According to the eligibility worker we interviewed, many eligibility workers are not yet aware of the advocacy program. The new advocacy program was holding meetings with different units in the county offices to inform them about the program.

Many of the referrals received to date in the program had been for children whose SSI applications were denied in the past. Few of the referrals made to date involved children in foster care. The advocacy program accepts all referrals and checks with SSA to understand the basis for denial. The program has had success with several of the approximately 150 referrals received to date. Some of these cases involved new applications while others involved children with earlier denials.

The staff member we interviewed noted that it had been somewhat difficult to assemble the resources for the program. The County is not reimbursed for funds expended so it has been important to convince the decision-makers that money is being saved by reducing caseloads for CalWORKs and General Relief programs. Procuring the necessary medical information had been an issue for adults in the General Relief population, but this was not reported to be a significant issue for children given that they are generally already enrolled in Medi-Cal. The program is considering several possibilities for funding. Medi-Cal managed care has made the process of gathering medical information more complicated because a referral from the PCP generally is necessary before the managed care beneficiary can see the specialist.

Observations of Family Impact

In terms of impact on children in protective services, the staff member we interviewed was not aware of a significant impact on SSI eligibility of children who are in foster care. No statistical data were known to be available on the exact numbers.

4.3.2 Fresno County Department of Community Health, Children and Family Services

We interviewed two administrators in the Department of Community Health, Children and Family Services. This department has administrative responsibilities for child welfare (child protective services) and for children's mental health services.

Roles for Children With Disabilities

The Department uses a combination of public and private providers to deliver mental health services for children. The Department has used relationships with the private sector when the volume of need exceeds capacity or when a need for a particular specialization arises. Under the transition to Medicaid managed care, the Department has managed the mental health carve-out.

Response and Observations of Policy Impact

The administrators described several aspects of mental health care for children in the county that might be relevant to children losing SSI. In terms of potential gaps in Medi-Cal benefits for children and certain limits to how county funds could be expended, one administrator noted that it has been difficult to extend services to those children who are without diagnoses but may be acting out behaviorally or have a severe conduct disorder. The administrator noted that such children who have not yet reached the point of delinquent behavior but are headed that way almost have to engage in delinquent behavior to get services. Emergency mental health services, crisis triage, stabilization, and longer-term assessments typically fall into the category of services that would be available. The administrators we interviewed felt that a significant number of children in the community may be affected by the service limitations. The County has been working on accessing other funds such as from child welfare to address this service gap.

While the Department has not identified specific outcomes of SSI, one administrator noted that the income loss could result in families waiting until a crisis developed because of their inability to access services on an ongoing, preventive basis. Families that do not access services until a crisis occurred might instead access the local Psychiatric Assessment Crisis (PAC) Team, which is a 24 hour hospital-based assessment facility for mental health. One administrator noted that the County was encountering a high number of children presenting to this facility at a rate estimated at around 65 children per month. Waiting until a crisis occurred also could result in a need for protective services. The administrators we interviewed stated that this has been a focus area for program enhancements. Recently, the County has been trying to build the capacity to have mental health clinicians respond in the field so that the children and families can be stabilized in the home. Another part of this effort involves the development of a children's crisis intervention resolution center that would be adjacent to the PAC. The goal would be to provide health care for medical clearance and assessment capacity within that setting that could then be followed by linkages of families to whatever services are needed. One administrator we interviewed stated that PAC had been developed for an adult population. Based on what the Department has observed in children's needs (primarily adolescents) and in the volume of children, the need for a specialized program had been identified.

One administrator noted that the number of children reaching this crisis stage had been increasing and that some of the same children continued to access these crisis services, although no clear explanation for this increase has been identified. The administrators we interviewed noted that this issue had caught the attention of the Department over the six month period prior to the interview. One administrator felt that it would be interesting to examine whether there was any association between the children who are using this system repeatedly and any changes to Medi-Cal coverage, the loss of SSI, or some other changes underway. The administrator stated that the Department needs to evaluate the adequacy of service availability in the community using a systems approach that would examine components such as after-care services, school-based services, and the different service providers that children may be seeing.

An administrator also noted that the County has been developing a closer relationship with the courts to address the needs of this population of children. Children who are within the juvenile justice or child welfare systems would already be under an existing court order, but the County would like to have better access to judges so that services could be ordered for other children on a 24 hour basis. This approach also could address the problem of authorization requirements that prevented physicians from prescribing necessary medications.

Observations of Family Impact

The administrators were asked about the possible impact of losing SSI-linked Medicaid eligibility. One administrator noted that it should not have an impact on Medicaid coverage for children in the foster care system. A child in a foster care placement could obtain Medicaid through their foster care status, and alternatively the County could cover the costs of needed medical care using county funds.

4.4 SUMMARY OF FAMILY INTERVIEWS

We interviewed nine families in Fresno County in the first round of case studies, during the week of October 26, 1998. The parents we interviewed reported that their children had the following diagnoses when they began receiving SSI: low birth weight-related problems; asthma and learning problems; attention and learning problems; low birth weight related problems and emotional disorder; attention disorder; attention and behavioral disorder; impaired motor function; learning problems; attention disorder with Tourette's syndrome and seizure disorder. We conducted follow-up interviews with eight of these nine families during the week of October 25, 1999.

4.4.1 Experiences with the Redetermination Process

Outcome of the Redetermination Process

In 1998, three of the nine parents reported that they never appealed. The remaining six of the nine families appealed the decision to terminate the child's SSI benefits either initially or following the "good news" letter. Of the nine children, one was receiving SSI benefits after a finding of eligibility. Four were still in the appeals process, and four had SSI benefits ceased and had no pending appeal.

In 1999, two of the eight families who were re-interviewed stated that the child's eligibility had been restored. The remaining six families stated that the SSI had been ceased and that there was no appeal pending. The family that could not be interviewed in 1999 had been in the appeals process in 1998.

Understanding of the Redetermination Process

One parent who was Spanish-only speaking stated that if her child was ever on SSI again, she would request that letters be in Spanish so that she could better understand the correspondence. One family that had exhausted all appeals stated that they did not understand why this child was not eligible for SSI while another child who they perceived to be less impaired had never had benefits taken away (although also subject to an eligibility review during the study period).

In 1999, none of the parents reported having missed appointments relating to the child's eligibility status. None of the parents whose child's cessation was under appeal stated that they did not understand why they had not heard from SSA on a decision.

Appeals and Benefit Continuation Requests

In 1998, only one of the six families who appealed stated that they had requested benefit continuation. In 1999, the family had recently been notified of a final cessation decision and been informed that they had incurred a sizable overpayment. The family did not report knowing about or believing they could qualify for a waiver of this overpayment. They felt that they could not repay the money and had not worked out a payment arrangement or begun making payments.

Another family that appealed but did not receive benefit continuation stated in 1999 that the child had been found eligible, apparently after a hearing with an ALJ. (This parent felt that the family had submitted a request for benefit continuation but had not heard back and thus did not receive benefits during the appeal). A dedicated account had been recently set up for this child with the retroactive benefits. The parent described this account as a "trust fund" for the child that could be accessed after the child's 18th birthday. The parent felt that this money could be used for medical emergencies or for a medical need or an educational need prior to the child's 18th birthday. The parent reported that they might access the funds for orthodontia for the child.

4.4.2 Impact on Medicaid and Health Care Access

Medicaid Eligibility and Enrollment

Two parents reported in 1998 that their children lost Medicaid (Medi-Cal) benefits after the SSI payments stopped. Medi-Cal eligibility was restored for one of these children when the child was hospitalized; the parent reported not pursuing it until the child became ill, at which point the parent went to the welfare office and was able to enroll the child in Medi-Cal. For the other child, the parent stated that she had been hoping that the SSI income would be restored and that the Medi-Cal eligibility would be restored at that time. We were not able to conduct a follow-up interview with this family in 1999.

One parent believed in 1998 that her child was still enrolled in Medi-Cal but was not sure because she had not tried to access services for the child. This parent planned to

enroll her other children (and this child if his Medi-Cal eligibility was terminated) in California's Title XXI SCHIP Healthy Families Program.

In the 1999 interviews, no additional families reported losses of Medicaid eligibility.

Enrollment in Private Employer-Based Health Coverage/SCHIP

Two children whose families were interviewed in 1999 were currently enrolled in private, employer-based health insurance. For one of these families, the child had been covered by private insurance even before changes to SSI eligibility, with Medi-Cal as the secondary payer.

For the second family, the parent had enrolled the child in the parent's employer-based health plan in mid-1999 due to a court order. The parent explained that a judge ordered that the child, who has been in foster care since around the time that SSI benefits were lost, be covered by the parent's health plan (although the parent reported not being covered by the plan due to affordability). The parent believed that this was because of a state or local policy to get as many parents as possible to take on more of the costs of a child in foster care.

This parent was continuing to pay a biweekly premium for the child's health insurance but due to its cost had submitted an application for Healthy Families (California's SCHIP) and also submitted a request to be relieved of this requirement. The Healthy Families application had been redirected to Medi-Cal due to income eligibility. The parent also explained that the child probably had never lost Medi-Cal eligibility. This parent also reported having explained to the child (an adolescent) that the family could not afford the co-payments and deductibles that would be incurred if the child used the private insurance. The parent had just been relieved of this requirement at the time of the interview.

None of the children was enrolled in Healthy Families Only one family had submitted an application to Healthy Families for a child who lost SSI

One parent was considering enrolling in a supplemental insurance plan that provided pharmaceutical and vitamin benefits, although the child continued to be enrolled in Medi-Cal.

Transitions to Prepaid Health Plans

In 1998, none of the families who were interviewed reported that their child had been required to enroll in a prepaid health plan (PHP), or had become enrolled in a PHP since losing SSI. None of the parents expressed concern that their child might have to enroll in a PHP or that such a transition might affect the child's access to care.

Five of the children whose parents were interviewed in 1999 were enrolled in Medi-Cal prepaid health plans, rather than in fee-for-service. One of the five children had been

assigned to a PHP since the 1998 interview; this child's SSI eligibility was under appeal and restored in 1999, and the parent explained that she did not select a prepaid health plan and instead was assigned to one.

Access to Medical and Mental Health Services

In 1998, two parents reported significant problems with accessing appropriate care for their children. In 1999, the parent of the child in foster care felt that the child had been able to access regular therapy or psychiatric services when in crisis foster care and family reunification care, but once in permanent foster care had not had the same level of access. This had been exacerbated by the child leaving a foster care placement that was part of a therapeutic program.

The second parent, who was having difficulty finding a psychiatrist whom she could understand, was not interviewed in 1999.

In the 1999 interviews, another parent raised some difficulties they were having in getting health care for their child (no longer on SSI). The child would not use the kind of asthma medication that Medi-Cal covered and the family could not afford the alternative medication that was apparently not on the Medi-Cal formulary. No other parents raised difficulties with accessing medical or mental health care. Several parents stated that their child was not taking Ritalin (one had not restarted the child on Ritalin at the beginning of the school year) because of side effects that also impaired function.

4.4.3 Socioeconomic Impact

In 1998, most families whose income declined reported that it was generally harder to cover household costs.

In 1999, one family stated that they continually rotated the name of the person on the telephone bill so that they could maintain phone service even though they could not always pay the bill. One parent who increased her working hours to compensate for the loss in income, and had subsequently placed her child in foster care, continued to pay child support for the child. Two other families were living in houses with an additional renter in one room, to help with the income but also for companionship and/or for some child care coverage.

Total Income Levels

In 1998, total family income was reported to have declined in all eight families who were no longer receiving SSI benefits. The one family that experienced an increase in family income was the family that had the child's SSI restored (and eligibility ultimately affirmed) and had successfully applied for Food Stamps as well.

By 1999, of the eight families who were re-interviewed, one reported that overall family income had increased (due to new child support payments and restoration of the child's SSI). One of the families whose income declined by 1999 was continuing to receive SSI for the child, but then lost SSI benefits for the child's adult sibling. In this family, the income decline was not attributable to the welfare reform changes. The other seven families reported that total family household income had declined.

While the focus of the interview was on income levels relative to the pre-redetermination period, some changes between the 1998 and 1999 interviews were described by families. Between the 1998 and 1999 interviews, family income increased for three families and declined for two families.

Four of the nine families were two-parent households. Of the five single parent families, two were receiving child support in 1998 and had been receiving this income since before the SSI stopped. In 1999, an additional parent had applied for child support and was beginning to receive sizable child support payments.

Work Participation

In 1998, in seven of the nine families there was at least one working parent prior to the changes in childhood SSI eligibility. The parent in two of the working families had increased their working hours in response to losing the SSI income. By 1999, parents in four of the working families had either increased working hours at the current job or taken on a new (additional) job. One parent had found a higher paying job by 1999.

Use of Public Assistance

In 1998, three of the families reported an increase in or new receipt of public assistance following the loss of the SSI income. One family maintained the same level of Food Stamps but increased the welfare benefit (AFDC/TANF). By 1999, the parent in this family dropped the welfare benefit due to knowledge of the 5 year time limit, and not wanting to reach the limit. This parent also dropped the Food Stamps benefit because the amount received monthly was quite small. Thus overall, two families increased their use of public assistance after losing SSI, and one family reduced their use of public assistance (though with a temporary increase immediately after losing the SSI benefit).

4.4.4 Caregiving and Other Child Impact

Living Arrangements

One family reported a change in living arrangements in 1998 due to the child entering foster care. By 1999, two families reported changes to household composition with both families renting a room to a friend of the family; one of these two families also moved between 1998 and 1999 due to being accepted for new housing assistance. One additional family interviewed in 1999 had changed residence, also due to being accepted

for new housing assistance. Other than the child who entered foster care (whose change was only partly attributed to the SSI loss), and one family that was renting a room to a relative, none of the families attributed the change in living arrangement, household composition, or residence to the loss of SSI. In the other two cases, the family felt that the change was partly due to losing SSI but also due to other issues (e.g., worsening behavior problems, receiving new housing assistance).

Child Care

In 1998, one parent said that she did not have childcare and that this was a problem for her youngest child (the SSI recipient). A change in working hours had resolved much of this problem by the 1999 interview. One of the families that had a new renter in the home received some child care help from the renter (a relative). No other child care issues were raised by families in the follow-up interviews.

Overall Family Impact

In 1998, we interviewed five families with teenage children. The parents of one of the two former SSI beneficiaries who were approaching age 18 were concerned about his future schooling opportunities and ability to do farm work due to physical problems. The parent of the other teen approaching age 18, also was concerned about his ability to keep a job because of problems with learning. These concerns were repeated in 1999 but neither teen had reached age 18 or left school.

In 1998, several specific issues were raised in the interviews that pertain to rural factors. Several parents stated that they relied on seasonal agricultural work to support their families, and felt that this made it difficult to receive public benefits due to the resulting income fluctuations. Limited rural work opportunities for the children also were raised by several parents. These issues were repeated in the 1999 follow-up interviews.

In terms of transportation for the families living in rural areas, in 1998 two of the three parents owned cars and thus did not report transportation to be a significant problem; this was not a significant issue in 1999 either.

5. SITE VISIT SUMMARY: HARTFORD, CONNECTICUT

5.1 INTRODUCTION

Connecticut was selected as a case study site due to a sizable but smaller volume of affected child SSI beneficiaries relative to other states, progress in welfare reform and generous Medicaid eligibility criteria, and its status as a 209(b) state in which SSI eligibility does not automatically confer Medicaid eligibility. We visited Hartford, Connecticut during the week of September 14, 1998 and during the week of October 11, 1999. We interviewed a total of eight families in addition to 13 individuals in eight different agencies.

In 1996, the State of Connecticut ranked 29 among states in the total number of children under age 18 (at 797,000). In terms of SSI participation in August 1996, Connecticut ranked 47 in the proportion of children under 18 on SSI (at 0.7 percent of children). Connecticut ranked 26 among states in the percent of child SSI beneficiaries with IFA (who represented 21.4 percent of the child caseload) and 47 among states in the percent of child SSI beneficiaries with maladaptive behavior (who represented 1.4 percent of the child caseload).

Hartford ranked first among counties in Connecticut in the total number of child SSI beneficiaries and the total IFA and maladaptive behavior cases (356). Hartford also ranked first in the total cases subject to redetermination (594) and in the total cases ceased with no appeal pending as of January 1998 (170). As of January 1998, Hartford ranked fourth among counties in the percent completed of those cases subject to redetermination (ranked 4 of 66 counties)—likely due to the relative size of the caseload—and in the percent of cases ceased with no appeal pending (ranked third with 28.6 percent).

Connecticut implemented statewide TANF welfare reform in October 1996. Connecticut offers transitional child care and transitional Medicaid for longer than 12 months for welfare beneficiaries who stop receiving cash assistance.

Connecticut is one of nine 209(b) states in which SSI eligibility does not automatically confer Medicaid eligibility. Connecticut also has had very generous Medicaid eligibility and extended eligibility to most children up to 185 percent FPL even before the Title XXI child health insurance expansion legislation was passed in 1999. Connecticut subsequently expanded Medicaid eligibility for children through 18 years of age to 185 percent FPL. Connecticut's state-only child health insurance program extends the state employee benefits package to children 0 to 18 years up to 300 percent FPL, with a premium buy-in provision for children in families above 300 percent FPL. Cost-sharing requirements are imposed for children in families above 185 percent FPL. In Connecticut, child SSI beneficiaries are not exempted from mandatory participation in Medicaid managed care. Both medical and mental health services in the Medicaid program are provided through managed care arrangements.

In the sections that follow, we repeat the format established in Section 3, first summarizing the interviews with SSA office staff, then with Medicaid and other public and private agency staff, and finally with families in Hartford.

5.2 SUMMARIES OF INTERVIEWS WITH SSA OFFICES

5.2.1 SSA Regional Office, Boston, Massachusetts

We interviewed two administrators in the Boston Regional Office. The Boston Regional Office covers seven states including Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont. The office has approximately 60 total staff.

Role in Policy Implementation

The administrators we interviewed stated that between the 1998 and 1999 interviews, the major focus of Regional Office activities for the childhood caseload has been to clear the re-reviews of the denials with mental retardation coding and the re-reviews of the redetermination cessations. There also was a listing of cases that were ceased due to failure to cooperate. Tracking and completing these cases have been the major focus. Some of the failure to cooperate cases involved recontacting the families and considering re-adjudication of the cases. Some cases involved technicalities regarding the case handling and whether the case was reviewed and coded properly. The tracking process had focused on these technicalities rather than on the actual adjudication of the cases.

Another emphasis reported by the administrators has been on speech and language pathology. As other issues with the childhood caseload were resolved, the speech and language impairments continued as an issue. Significant challenges included the evaluation of speech and language in children and putting the staff in place to perform these evaluations. The regional office has trained two speech and language pathologists for the regional quality group. The administrators we interviewed stated that the Regional Office also has encouraged DDS offices to hire or to designate speech and language pathologists who will perform these evaluations and also has encouraged the DDS offices to ensure that the cases get to those individuals for review.

In terms of permanent changes that have come out of the welfare reform changes to childhood SSI, the most significant reported was the involvement of speech and language pathologists in the SSI childhood program. The administrators we interviewed also pointed to a greater sophistication on the part of examiners in adjudicating cases that involve mental deficiency. There also appeared to be greater emphasis in getting psychologists involved.

One administrator we interviewed noted that there was greater reliance on the school system than there had been prior to welfare reform. This was attributed to the fact that the schools are where some of the speech and language problems and learning

disabilities for children are first identified and evaluated. This reliance on the schools was expected to be a permanent change.

Another permanent change identified by the administrators focused on determination of functional equivalence. In the past, a disability examiner might not dwell on functional equivalence if it was possible to go to the next area in the *Zebley* guidelines to domains of functioning. The case could be decided with three areas that were moderately restricted in the domain. Without the IFAs and without moderate impairment, there has been greater focus on the functional equivalence to make sure that the child cannot be allowed. Assessing the functional implications has been more challenging for the physicians and the examiners relative to determining medical equivalence.

Agency Impact and Challenges

Staffing and training. One change between 1998 and 1999 was the assignment of a DDS staff member to the Regional Office to help with tracking the childhood cases and ensuring that the reviews are completed.

According to the administrators we interviewed, the smaller DDS offices have fewer cases that involve speech and language issues. This has made it more difficult for these offices to justify hiring speech and language pathologists. In addition, it has been difficult to find speech and language pathologists to work for the DDS.

One administrator noted that all of the re-handling that occurred with the childhood caseload had created some morale problems at the field office and DDS levels. The reason given was that the cases continued to be returned for re-handling and this was thought to have created some frustration among staff. The administrators we interviewed felt that this situation should improve as the small number of remaining cases were completed.

Implementation. Over the past year, the challenge has been to locate the cases for tracking. Many of these cases had been handled multiple times due to the complexity of the redetermination and re-review process. One administrator felt that while a more sophisticated approach had definitely evolved in evaluation of mental deficiencies and of speech and language impairment, the concepts of adjudication had not been very complex over the course of the implementation. The source of the complexity was the technical handling or processing of cases. Because of the high visibility of the childhood caseload, there were many case processing codes that needed to be assigned to the cases. The disability examiners focused on making the right decision with respect to the child's eligibility but did not always get the coding straight for the purposes of the federal quality reviews. Some of the re-noticed cases returned for adjudication before a review could take place for a case in a re-review workload. Each of the subgroups required different coding.

There also were lists of cases that were returned for coding, rather than for anything having to do with the medical disability adjudication. The re-review tracking process

added new coding requirements to the existing case coding system. The administrators we interviewed also stated that the coding system as well as the process of sending cases back and forth between DDS and field offices contributed to confusion. For example, a case might be returned to a field office for development as a review of a cessation, but confusion at the field office could result in a new application. Another example was that a field office might send the most recent eligibility decision but not earlier decisions to the DDS for review. The administrators we interviewed stated that as the lists of cases were cleared, the staff found that most cases had been properly handled.

In terms of the impact on specialization versus a generalist field office design, the administrators we interviewed did not report any specific differences in case processing or in policy impact for the particular office. One administrator did note that in the smaller offices, there was low volume of each type of case. Because different examiners might handle all types of cases, the determination process might not be as familiar as it would be if the examiners were specialized. The larger field offices also may have a SSI childhood unit supervisor who would be familiar with all types of cases.

An ongoing challenge had been developing cases when schools are out for the summer. This was particularly for an area such as speech and language. One administrator noted that areas with a large bilingual population pose particular challenges. Part of the challenge comes from the standardization of testing for non-English speakers and the need to examine a person in their own language. This can create staffing challenges. In speech and language, it can be more difficult to identify problems for children whose primary language is not English.

Another reported challenge focused on children in out-of-home placements. In larger cities where there are large numbers of children in protective services, there can be multiple people involved in assembling the child's medical information. These individuals include the person who files on behalf of the child, the social worker in the field, the foster parent, and potentially others. The administrators we interviewed felt that this introduced difficulty in tracking information about the child. The offices with large populations of children in out-of-home placements have this more difficult caseload to process. One administrator noted that the local offices had put significant effort into ensuring that eligibility not be denied for a child in foster care due to cooperation issues. As a result, there can be an extended process that involves multiple administrative levels of a child welfare department. The administrators we interviewed were not aware of any differences across the States or cities in the region in terms of whether the child welfare agencies could accept and manage dedicated account funds for children.

The administrators we interviewed observed that the age 18 cases had not posed any particular implementation challenges. In terms of eligibility determination issues, eligibility for children under 3 years of age was felt to be more challenging. In contrast, the age 18 population in general has a relatively stable level of functioning.

The administrators we interviewed were not aware of any specific roles of the DDS offices or of differences across the DDS offices in determining the disability status of children within the Medicaid grandfathering provisions.

Caseload Status

The administrators we interviewed reported in 1999 that the childhood caseload was nearly completed with approximately 50 cases still pending. In terms of the appeals process, the regional office did not have current figures on where cases are in the appeals process. The office also did not have specific figures on the volume or rate of new applications from the children whose SSI benefits were ceased based on the welfare reform changes.

The administrators we interviewed had not perceived any specific changes in the volume or type of childhood applications that had been filed in the post welfare-reform period. One administrator noted that with the DA&A caseload, it appeared that individuals who were alcoholics and whose underlying disability element was the excessive drinking, began to emphasize depression or a similar impairment. The administrator had not perceived that redetermination of the childhood cases had resulted in their families emphasizing different aspects of the child's disability in this way.

Differences in Impact across States

The administrators that we interviewed did not report any additional, significant differences in implementation or impact across the States, other than the differences for cities with large child welfare caseloads, the differences in the bilingual populations, and the differences in availability of speech and language experts. While some of these differences occurred within as well as across states, specific challenges with respect to speech and language evaluation were identified for one state. It was reported that in Rhode Island, progress notes have been difficult to procure for children in speech and language because of the shortage in pathologists and thus their limited time with the children. A related issue was that a child may not have a regular speech and language pathologist because the pathologists serve the entire state. This has made it difficult for SSA to assess the rapid changes that can occur with school age children.

5.2.2 SSA Disability Determination Services (DDS), Connecticut

We interviewed two individuals in the Hartford area DDS in 1999, including a medical liaison and a supervisor for the childhood SSI disability unit. The DDS had the same number of examiners in both 1998 and 1999 but had approximately 14 new medical consultants in 1999.

Role in Policy Implementation

The administrators whom we interviewed in 1998 reported increased activity in public relations and in community education about SSI since the 1996 welfare reform law. Both staff members we interviewed in 1999 reported that they had continued to perform a significant amount of public relations activity relating to the childhood SSI. The staff members indicated that each contact with a provider or agency provided an opportunity to convey the policies of and eligibility for the SSI program. SSI eligibility is so complex that it cannot be conveyed through brochures and such materials.

Several DDS staff met recently with the new staff person at the Title V Children with Special Health Needs program to review the referral process and the disability codes used by SSA. This is part of the ongoing relationship between Title V and SSA, in which SSA sends information to Title V on all affirmed and all denied SSI applications for children. This enables the Title V program to screen these referrals to determine which of the applicants might be eligible for services such as Title V Children with Special Health Needs, and Zero to Three developmental services. DDS staff helped explain the diagnostic codes that they used so that Title V staff can better assess potential eligibility for other programs.

Agency Impact and Challenges

Staffing and training. A significant challenge that was reported to have continued into 1999 involved speech and language consultation for childhood cases. The administrators we interviewed stated that SSA policies required hiring at the PhD. or physician-level for consultative medical staff but that there were few or no individuals with that level of training in speech that the DDS could hire. According to the staff we interviewed, this was partly due to inadequate local capacity in such expertise and partly due to the fact that few people receive formal education in speech issues beyond the master's level. The DDS has been trying to resolve the ongoing need for speech medical consultation expertise. The administrators we interviewed noted that the DDS had one pediatrician who was reading literature on speech issues to learn as much as possible. The DDS had additional plans underway to address the challenge.

Supervising staff continued to reinforce to DDS staff how to handle the age 18 cases. According to one administrator we interviewed, often staff appeared initially to look at these cases as CDRs with an improvement standard, which should not be applied to these cases, rather than applying only adult criteria. One reason there has continued to be the need to clarify instructions to staff was that the age 18 cases were handled by staff across the DDS, rather than within the specialized childhood unit. An issue with the age 18 cases has been that each examiner may receive a small number of these cases. Because these cases are a fraction of the cases that an examiner receives, examiners are less familiar with them. The staff we interviewed suggested that it might be helpful to have a separate form for the age 18 cases so that staff would be less likely to get confused about how to handle them.

Implementation. Getting school records continued to be a challenge to the DDS in 1999 as it had been in 1998. Schools had been warned early in the childhood redetermination process that they should expect an influx of requests from the DDS. This was a significant issue in Connecticut where there are over 110 towns with each having a separate school district. Each school has a different filing and record-keeping system that the DDS encounters. Moreover, the schools generally did not have staff support to complete the copying of records that was necessary to meet DDS needs. Such record copying also appeared to be relatively low on a school's priority list. While the Board of Education administers the allocation of funds it has not coordinated other school processes. Also, schools do not by rule have written speech therapy notes. The feedback received by DDS from the schools has been that the schools do not intend to change their policy to provide the written notes needed by DDS for the eligibility determination.

The staff we interviewed suggested that it was important for state/local differences to be taken into account by the Baltimore Central Office in the implementation. One staff member suggested that it might have helped to have the Baltimore Central Office develop a letter for distribution to the schools because it might get schools behind the eligibility determination effort.

To overcome this challenge, the DDS had tried to provide necessary resources to the schools, such as postage-paid envelopes and fax capability. The DDS offered copying resources to schools, but generally schools were unwilling to provide DDS with direct access to records.

The DDS has received some complaints from schools and physicians about the volume of paperwork that is required for childhood SSI applications. The staff we interviewed also provided examples of contacts with providers in which the provider argues that an affirmation of SSI eligibility could even have a potential negative effect. For example, a social worker might argue that giving SSI to a child might cause them to drop from treatment, while a vocational trainer might argue that a child is close to completing a course of vocational training and might terminate early with a finding of SSI eligibility. One physician has expressed to a staff member not wanting to submit paperwork for some patients with asthma.

The administrators we interviewed felt that in general, many providers do not understand why SSA requires certain tests that providers generally do not perform and information that generally is not recorded by providers. The forms and information requirements are now quite complex. Speech was emphasized as a complex area. One of the staff members we interviewed observed that when decisions using detailed information required on speech were re-assessed using more readily available information, there were differences in the decision that would have been rendered. The administrator noted that the additional information has tended to increase the confidence of the examiner in the decision but rarely resulted in a denial becoming an allowance.

In the near future, the staff we interviewed felt that coding of "treatment" status on the 831 form would be the next area for focus and challenges. At the time of the interview,

the DDS was assigning codes indicating whether required treatment is ongoing or not being received. IVT training had been provided approximately 6 months prior to the interview on this coding process stemming from welfare reform. So far, the staff we interviewed felt that most forms had been coded as “in treatment” but were not sure how this information would be used at the field office level where responsibility for acting upon the treatment coding would rest.

Medicaid eligibility was not considered to be an important issue because Medicaid and SSI eligibility are not linked in Connecticut. Parents had expressed concern about Medicaid coverage continuing during and after the SSI eligibility redetermination, and a fact had expressed more concern about Medicaid coverage continuing than the SSI benefits. The administrators we interviewed noted that the Husky (SCHIP) program had been quite successful in the state in enrolling low-income children.

In terms of overall impact, one staff member we interviewed felt that it had taken three years since welfare reform to develop a well flowing and timely process. Coding was reported to still be very complicated with the challenges related to coding continuing even past the difficulties incurred in tracking redeterminations, reviews, and other case reviews following welfare reform and the Commissioner’s Top-to-Bottom review. The significant changes that had taken place over the past few years appeared to have been hardest for examiners with the longest tenure.

The staff we interviewed felt that the changes that resulted from welfare reform have produced an educational experience for the office. There was now a focus on evaluating a child “holistically” with attention to developmental and learning sequelae of a given medical condition, for example. Another observation was that families needed to have someone in touch with them in terms of transitioning from school to work or into work in general. The administrators observed that an approach involving more contact with families might have a greater likelihood of success than a system that relied on written materials to inform recipients about treatment requirements and related SSI program policies.

Caseload Status

The DDS had completed most of the redetermination and rereview and renoticed cases by 1999 with only a handful remaining. The administrators reported that some redetermination cases from the New York caseload had appeared in Connecticut as the family applied for government assistance. Many cases have reached or been heard by administrative law judges..

Experiences With Family Response and Impact

Few new applications have been seen for former child SSI beneficiaries whose eligibility was ceased following welfare reform. The staff we interviewed felt that the reason may be that the field offices have been very liberal in allowing “good cause” for late appeals (of terminations) that could have been as much as one year after the due date.

Consequently new applications for former beneficiaries were often handled as appeals. This may explain why new applications filed by former child recipients have not been an issue for the DDS.

5.2.3 SSA District Office, Hartford, Connecticut

In 1999, we interviewed two claims representatives in a SSA field office. A supervisor who works with a number of northern Connecticut field offices on SSI issues also participated in the interview. The total number of claims representatives in the office was reported to have increased slightly between 1998 and 1999. This had occurred due to the designation of the SSI program as high risk program and due to the implications of welfare reform for caseloads and staffing.

Role in Policy Implementation

In the 1998 interview, it was reported that the entire staff was trained on how to handle the childhood cases because of the large volume of childhood cases for which eligibility needed to be redetermined. The staff we interviewed in 1999 indicated that the age 18 cases seemed much more complex and had involved a significant checking and comparisons within the field office. The office continues to specialize functions, and it is expected that the office will remain specialized for the foreseeable future.

Agency Impact and Challenges

Staffing and training. The staff members we interviewed felt that field offices that use the generalist rather than the specialized organization were having more difficulty with the welfare reform changes. The offices that had taken the generalist approach and that may have placed higher priority on Title II claims relative to Title XVI (SSI) claims in the past appeared to be experiencing more difficulty adjusting to the childhood changes. The staff we interviewed perceived that the office we visited was handling the welfare reform changes better than many other offices because they had built up SSI resources prior to welfare reform. The staff also felt that the specialist approach had helped in the redeterminations because those staff members who did not work on many SSI claims were not as familiar with how to handle them.

Implementation. According to the staff we interviewed, the office had been very liberal in granting good cause to families who filed late appeals for the child. This was offered as one reason for their observation that the office has not seen a many new applications from families whose children were on the rolls in 1996 and subsequently lost SSI benefits.

Getting the Department of Children and Families to meet the requirements of the SSI eligibility determination process in a timely way for children in out-of-home placements was reported to be a continued problem in 1999. It has been difficult for field office staff to get the necessary forms completed and returned on a timely basis and has

required vigilance and effort on the part of field office staff. The staff we interviewed felt that part of the problem was that many individuals within the DCF agency are involved in the process with a different person reviewing and another signing the paperwork, for example. Sometimes files for children in foster care are missing necessary information. One claims representative we interviewed stated that continual follow-up had been necessary with occasional notifications to DCF that SSA could no longer hold the case of a particular child if DCF did not send the necessary information. Name changes and residential moves of children in out-of-home placements added to the difficulty of conducting redeterminations for this group of children. According to the field office staff we interviewed, another issue that had emerged specifically for DCF was that the state was not able to accept the requirements of the dedicated accounts. As a result, the dedicated account funds that resulted from successful appeal without benefit continuation for some children in out-of-home placement have remained as underpayments in the SSA system. This issue is discussed further in Section 5.4.2.

The claims representatives perceived that one overall effect of welfare reform has been that the childhood cases in particular in the SSI program have become much less routine. Overall, the staff we interviewed felt that everything about the childhood SSI caseload has become more complicated with changes in parent work status, in wages, and in use of bank accounts, for example. Many of these changes did not result from childhood eligibility changes but instead from the broader changes involved in the welfare reform law. In the past, families tended to have few other income sources (e.g., public aid) and this income was stable from month to month. In contrast, at the time of the 1999 interview, most parents were working and families had multiple and changing sources of income largely from earnings and from child support. Because these new income sources could vary significantly from month to month, it was necessary for field office staff to assess household income more frequently than had been done before. The CRs also reported that parents were beginning to demonstrate a better knowledge of income reporting requirements because they were now making these reports on their total income and work hours more regularly. In fact, one staff member we interviewed noted that some parents were now referring to the claims representative they communicate with as their "caseworker".

According to the staff we interviewed, the field office had experienced some difficulty getting information about child support payments that may be coming into a household of a SSI recipient because child support was not part of the regular disclosure agreements that SSA has with the social services agency. Child support payments are handled by a different agency and the staff we interviewed reported that the child support information was considered to be private. The CRs we interviewed stated that sometimes it was more expedient to ask a parent to request the child support information from the agency and for the parent to then provide this information to SSA. The staff stated that not being able to get this information directly from social services caseworkers posed problems because such payments often fluctuated. There might not be any payments for a few months and then a lump sum payment made because the absent parent got a new job, for example. The staff we interviewed felt that the problem was one of confidentiality but

that the caseworkers who handled the child support information on average seemed knowledgeable and helpful.

A new challenge for the field office may be dealing with the requirement that SSI recipients comply with medical treatment as deemed appropriate. The staff we interviewed explained that the DDS uses coding to indicate to the field office whether a payee is complying with medical treatment. This process was reported to have just begun at the time of the 1999 interview. It was reported that staff would need to further examine the policies and procedures on which they were trained earlier in 1999 on how to handle these cases as the volume grows. One staff member we interviewed suggested that this may not have a significant impact on the field office because a larger proportion of children now on the rolls had medical problems that involved more physician contact and more regular medical care. As a result, it was not expected that the DDS and field offices would find a very large number of childhood cases in which not being in medical treatment would be an issue.

Dedicated accounts. Dedicated accounts remained a major problem for the office in 1999, according to the claims representatives we interviewed. Some staff characterized the dedicated accounts as a policy failure. The CRs we interviewed stated that it was not practical to give money to low-income parents and then tell them that they could not use the funds. Parents generally did not appear to understand why they could not use the dedicated account funds for clothes and toys for the child. The staff we interviewed felt that they had made decisions that were very consistent with the dedicated account rules. The CRs we interviewed mentioned several examples where they felt that had “stretched” the policy to allow certain family expenditures. In one case a psychologist had contacted the field office to confirm a mother’s request to use dedicated account funds for a child’s trip to stay with the father for a time period due to the child’s behavior problems. The dedicated accounts have taken a significant amount of time and effort in staff follow-up. The dedicated accounts policy had resulted in many hours of staff overtime trying to figure out what to approve and disapprove, and trying to contact the families and manage the requirement that families pay back funds that were misapplied. Some of the CRs we interviewed felt that implementing the policy was not cost-effective because of its tremendous cost to administer relative to the gain that it achieved.

The staff we interviewed identified some ways that the intent of the dedicated accounts could be met by a different account structure. One staff member suggested that the dedicated account funds could be placed in a trust for the child like other payments of this sort. Then there would be someone who could dispense the funds based on the parent’s application. Alternatively, one staff member suggested that a process could be put into place in which SSA staff would receive requests from parents on how to spend dedicated account funds, and would then approve or disapprove the uses. Parents would then learn after a few requests what kinds of expenditures would be approved. One claims representative suggested that while it would be time consuming, it would be more cost-effective to have CRs dispense the funds in a dedicated account upon request, rather than to instruct families on appropriate uses and then have to expend effort after the misapplication to get money paid back.

When misapplication of funds was found (as differentiated from misuse of funds, which requires a change in payee), parents were required make payments to SSA. Such cases could be referred to the Department of Justice for collection. According to the staff we interviewed, some parents have appealed to the ALJ level regarding their dedicated account. It appeared that ALJs were allowed to be (and appeared often to be) more lenient or “looser” in interpretation of appropriate uses. ALJs appeared to actually have reversed some findings of misapplication. The CRs raised an example of a case where the ALJ finding was inconsistent with the SSA policies and procedures with respect to appropriate uses of dedicated account funds.

Caseload Status

The office was reported to be current with the CDR process. The redeterminations, re-reviews, and re-noticed cases had been largely completed. Several cases were still unfinished at this time and are generally cases in which the parent could not be contacted. Staff reported that in some of these very few cases, the field office has been asked to contact the parent even though there is incomplete contact information and the parent cannot be contacted. The office also has continued to see appeals. A number of cases had gone through the ALJ reviews and were pending at the Appeals Council. The staff we interviewed was aware of some cases in which the ALJs had reversed the earlier cessation.

Experiences With Family Response and Impact

The claims representatives we interviewed felt that the majority of parents (nearly all parents) had appealed when their child's eligibility was ceased. In 1998, the staff we interviewed indicated that those parents who were working and receiving relatively small SSI amounts appeared to be less likely to appeal. In 1999, the staff indicated that the majority of parents asked for payment continuation. The few parents who did not request benefit continuation may have made this decision in the earliest days of the redetermination process, when the information provided to parents made the waiver of overpayment payback requirements sound like a less likely possibility. The claims representatives stated that it was not clear how well parents understand that they can ask to waive the overpayment payback requirement. Often the parents had not responded to notification that they had been overpaid for an appeal when the cessation was upheld. The staff we interviewed speculated that these families may ignore these letters rather than finding out more information about the overpayment and waiver provisions. This has occurred even though it is very easy to request a waiver, and claims representatives are generally willing to waive the overpayment as long as the parent has pursued appeals in good faith believing that the child could still be found eligible. An example of a rare instance in which a waiver had not been granted by a claims representative was a parent who had not attended her child's hearing, and who did not respond to an effort by the hearings officer to re-schedule the hearing.

One observation of a claims representative was that if the checks have been discontinued, then the parents have no incentive to ever call or contact the SSA office

again. A separate office handles the overpayment process. If the parent is paying back the money, then the SSA field office does not hear anything about the case. If the parent does not pay it back, then the field office would be likely to hear about it. The staff we interviewed noted that there may be families who are paying back the money and who might not have to repay these funds if they filed a waiver with the field office.

For parents who do not repay a required sum, the funds may be withheld from the parents' tax refund. SSA can take the overpayment from the refund based on a SSA/IRS agreement. Staff anticipated that those parents who do not receive their full refund may then contact the SSA field office to find out the reason. According to the staff we interviewed, parents had generally not responded to letters warning them of potential withheld amounts from their tax refunds.

It was reported that at the time of the 1999 interview, most mothers were reaching their 21 month time limits and losing public assistance due to TANF implementation. Most parents were now working. One staff member observed that there seemed to be more fathers living in the home, or at least that more families were reporting that the father was now living in the household. The staff member speculated that there is no longer an applicable "penalty" for having the father in the home either because the family is no longer receiving public assistance or because public aid rules changed with respect to the father counting as part of the household. The CRs also perceived that child support had increased significantly over the past years as a source of income. Part of the welfare reform changes in Connecticut focused on identifying absent parents and garnishing wages.

It was the perception of the staff we interviewed that the local community has learned about the eligibility changes for children, and that fewer applications were coming in and/or that fewer applications were being approved. Another reason for seeing fewer applications may be that household income has been rising due to parents going to work with SSI no longer worth the effort of application for as many families. Once denials come from new applications, the staff we interviewed felt that parents seemed not to be appealing as frequently as had occurred in the past. The staff we interviewed did not know whether this was due to different perceptions about eligibility or appeals or whether it might be because the letters that families receive now provide a better explanation of the reason for the negative decision.

A new situation reported by staff was that some parents whose child's new application was turned down then end up reapplying many months later. The CRs speculated that this may be in part because in the past, the state/caseworkers would follow-up with parents about their SSI applications and might encourage them to appeal. However, now that parents are in the workforce, they may have less contact with the caseworkers and thus receive less stimulus to reapply. Now parents appeared to reapply when triggered by losing work, reducing hours to part-time work, the deterioration of a child's health status, or encouragement from a teacher for reapplication.

The CRs stated that some parents have thought that Medicaid and SSI are linked in Connecticut. Those families who asked for benefit continuation also assumed that Medicaid would also continue. Parents were told that Medicaid eligibility would not necessarily be ceased if SSI payments were ceased. According to the staff we interviewed, the state's Child Health Insurance Program (Husky) has done a lot of outreach and seemed to be reaching a large number of families in the state.

5.3 SUMMARY OF INTERVIEW WITH MEDICAID AGENCY

We interviewed an administrator of the State of Connecticut's Medicaid program in the Department of Public Social Services in 1998. We did not complete a follow-up interview during the 1999 field period. The following paragraphs report on our findings from the first round interview. Connecticut is a 209(b) state that does not confer automatic Medicaid eligibility to SSI recipients. Because Medicaid and SSI are not linked, the content of the interview focused on what information had been provided to families about welfare reform changes, and on what coverage options existed for children who reached age 18.

Response to the Policy Implementation

Because Connecticut is a 209(b) state that does not link Medicaid eligibility to SSI status, the Medicaid program did not have a significant role to play in the implementation of welfare reform as it pertains to SSI. By 1998, Connecticut's Department of Public Social Services (DPSS) had sent notices to families of affected children informing them about their Medicaid eligibility, using listings of names provided by SSA.

Impact on Children's Medicaid Enrollment

The administrator we interviewed in 1998 did not know of any instances in which children lost Medicaid as a result of losing SSI in the eligibility redetermination process. Most children would have been in the Ribicoff eligibility group (meeting the AFDC or medically needy financial requirements but not AFDC categorical requirements) or a TANF (cash assistance) linked eligibility group. The administrator noted that child SSI beneficiaries who are affected by the age-18 redetermination policy could experience changes in Medicaid eligibility however. Connecticut extends Medicaid coverage up to 185 percent of the FPL through age 18. Individuals ages 18, 19, and 20 could receive Medicaid through the Ribicoff group or alternatively as disabled adults. If an individual is receiving Medicaid through a disabled adult eligibility group, then parent income and resources do not count in determining the individual's Medicaid eligibility. However, for individuals in this age group who are in the Ribicoff eligibility group, parent income and resources are counted in their eligibility determination. As a result, some 19 and 20 year olds could potentially not qualify for Medicaid.

Impact on Children's Access to Services

In Connecticut, enrollment in managed care plans has been mandatory for most child Medicaid beneficiaries. The exception has been children who are institutionalized or in long term care. SSI recipient status has not conferred any exemption from managed care participation for children in the community.

5.4 SUMMARIES OF INTERVIEWS WITH OTHER AGENCIES

5.4.1 Department of Social Services, State of Connecticut, Hartford

We interviewed a field manager and a unit supervisor in the Hartford Regional Office of the Department of Social Services. The responsibilities of the office include the operation of family independence units that have responsibilities for clients receiving cash assistance, Food Stamps, or medical assistance. The office and also has responsibility for child support operations.

Role in Policy Implementation

Many parents were reported to be entering the labor force due to TANF requirements. In terms of work participation requirements in Connecticut, families generally are not excluded from the TANF work requirement provisions based only on the fact that a child in the family receives SSI. According to the staff we interviewed, many of these children are able to attend school, and consequently the parent is able to work. If the parent is unable to work due to being the sole caretaker of a child who requires a level of caretaking that interferes with work participation, then the office would request medical documentation from the family. This can result in an extension of the period of time that public assistance can be received before time limits take effect. It can also result in a family receiving an exemption from the work requirements if it is required by the family's circumstances. A family could receive extensions of public assistance as well as the work requirement exemption. Thus there are ways that parents of affected children could be exempted from the work requirements and time limits.

The staff members we interviewed reported that a major issue for families has been child care. This includes finding a child care provider and also finding a provider given a child's particular disability. The staff noted that there are ways that the TANF program makes allowances for parents of children with disabilities. Usually a parent cannot base an extension request on having been fired or quitting a job. However, if the parent cannot hold the job due to child care problems, then extensions can be granted.

The agency was reported to be actively working to expand capacity in child care for children with special health care needs at the time of the 1999 interview. For example, there is a child daycare center that may expand its capacity. The state does pay a different rate for children with special health care needs, based on a specific child care regulation and associated policies and procedures.

According to the staff we interviewed, the interface between SSA information systems and social services information systems works well. The staff we interviewed was not aware of any problems that had come up in ascertaining a child's SSI eligibility status or the child's appeal status.

Observations of Family Impact

According to the staff we interviewed, a significant increase in the caseload associated with the changes to children's SSI eligibility has not been observed. One staff member stated that most families already were receiving public assistance and thus would add the affected child to the family's grant if SSI benefits were lost. (SSI income is excluded from a family's financial eligibility). In a few cases, the family was not receiving public aid and has newly filed for public aid due to the loss of SSI income.

5.4.2 Department of Children's Services, State of Connecticut, Hartford

We interviewed two Department of Children's Services (DCF) staff in the Revenue Enhancement Division with administrative responsibility for SSI and for other revenue sources for children in protective custody.

Approximately 188 children who are in protective custody (e.g., in foster care, group homes) in the state are receiving SSI. There are approximately 6,700 children in foster care and 2,300 children in adoption arrangements. The largest group of children in foster care comes from the Hartford area.

Response and Observations of Policy Impact

The DCF had continued to track the SSI eligibility determination process for children in custody. As in 1998, these cases were tracked by the SSI liaison in DCF who coordinates communication with SSA on all SSI eligibility issues for children in out-of-home placements in the state.

DCF also has tracked children in foster care whose cases had gone through the CDR process in 1998 and 1999. This included approximately 72 children. One of these children had left DCF during the time period. Of the 72 children, 27 had completed the CDR process. Of the children who had completed the CDR process, seven had been ceased and 19 had their cases continued.

As reported in the first round interview, DCF does not accept SSI payments for some children who are eligible for cash assistance through Title IV-E of the Social Security Act (see footnote 1). The staff we interviewed in 1999 estimated that this occurs for approximately 60 of the 188 children. The reason is that the federal match for federal Title IV-E payments for children in foster care can exceed the maximum amount of the SSI payment. The state receives a 50 percent Federal match for Title IV-E funds. The maximum monthly SSI payment is approximately \$500 per child. Thus if the Title IV-E

state share is less than \$500 monthly, then the state will accept the SSI payment. Otherwise the state will access Title IV-E funds for the child. As described in the 1998 interview, DCF is able to suspend SSI payments for up to eleven months per year. This maintains the child's SSI eligibility but enables the state to receive federal Title IV-E funds for the child.

The staff we interviewed explained that medical eligibility information is gathered by the case workers, who also attend SSI hearings occasionally for children in out-of-home placements. In general, it was felt that DCF would not continue to appeal a child's cessations repeatedly—such as following a cessation after the OHA hearing—because of the administrative burden that the appeals process places on the agency. The staff we interviewed stated that DCF has only tracked and contributed medical information to the hearings level for children in foster care. It was noted that case workers do not have the time to collect the appropriate medical information in a timely manner. Compiling the paperwork for each eligibility determination poses a significant administrative cost with a questionable return. The DDS and SSA require a significant amount of very complete medical information.

The challenge of dedicated accounts was not identified as a major problem for the agency because there have only been about 5 children who have had dedicated accounts established. Few children have had overpayments large enough to result in a dedicated account. To accept the dedicated account funds, the staff explained that DCF would have to establish the separate accounts, have the Treasurer approve them, and then create a process for auditing and spending the money according to SSA limits. This set of activities had not been possible for DCF.

The staff we interviewed expected that the workload for the SSI liaison would continue as the CDRs continued. It was estimated that these SSI activities comprise 30 to 40 percent of this individual's workload. The large volume of redeterminations was reported to have been the most difficult part of the childhood changes to handle in terms of staff time. It had been a time consuming process because each child's case must be handled individually.

The staff we interviewed did not expect that the caseworkers in DCF would necessarily become more efficient in handling the eligibility process because the cases are distributed across a large number of caseworkers.

5.4.3 Department of Children and Families, State of Connecticut, Hartford

We interviewed an administrator of mental health services in the Department of Children and Families, in the State of Connecticut. Connecticut is one of four States with a consolidated children's services agency. The Department includes child protective services/child welfare, juvenile justice, prevention, substance abuse, and mental health. The Department of Mental Health and Addiction Services provides services for adults.

Role for Children with Disabilities

The administrator we interviewed noted that many of the resources are invested in child protection and child welfare. Many of the funds within child protection and welfare are mental health funds. Mental health funds child guidance clinics as well as the residential treatment centers which serve children who have severe mental health problems, including children who have behavior problems that prevent them from living at home. Funds to these clinics are used to provide access to care for children. Other funds are directed toward special community-based programming for children, such as emergency mobile psychiatric services, respite care, extended day treatment, therapeutic visitation and reunification, and family preservation, for example.

The transition to managed care has encompassed medical as well as mental health services. Most Medicaid services have been privatized and are delivered through managed behavioral health programs. Each managed care plan that contracts with Medicaid is associated with a specific behavioral managed care plan. The administrator we interviewed stated that administrators from the department have been involved in explaining to the Family Support agency that oversees the managed care system what services should be reimbursed and what services are needed by the population with respect to mental health. Recent discussions have focused on home-based care and on the content of extended day treatment and its relationship to medical necessity for example. There also has been continued direct dialogue between the department and the health plans.

The administrator was asked how the use of managed care for behavioral Medicaid services might affect families' access to services. The implementation of managed behavioral health services in Medicaid was reported to have caused a significant shift in emphasis. The shift was reported to have introduced accountability but also to have involved paperwork and administrative requirements that were difficult for providers and clinics. The administrator we interviewed indicated that there had been progress in reducing the number of times that an authorization needs to be sought for mental health services. An example of such progress was a health plan shifting from authorization every 3-4 sessions to every 20 sessions.

Observations of Family Impact

The administrator whom we interviewed was not aware of any special impact of welfare reform on children receiving SSI, or the impact of the income loss for this group of children. In terms of overall family issues, substance abuse was reported as a continuing problem.

Other provisions of welfare reform had caused a more visible impact. Overall, the administrator we interviewed reported that one effect of the welfare reform "back-to-work" requirements has been that families are less available for services. For example, it has been difficult for a provider to conduct supervised visits at the same times during the day that these visits used to take place. In the post welfare reform period, these visits need to be done in evenings or weekends, for example. This was reported by the

administrator we interviewed to stretch available services in public and private sectors and to pose challenges in staffing.

Many families continued to be living in poverty even though they are in the workforce. The administrator we interviewed reported that families often do not have benefits associated with those jobs. In terms of the impact on parents specifically and on family functioning, entry into the workforce had been a positive change for some families.

5.4.4 Department of Mental Retardation

The administrator we interviewed in the Department of Mental Retardation in both 1998 and 1999 was not aware of any children served by the Department having their SSI eligibility affected by welfare reform. Because children must meet the definition of mental retardation to be eligible for DMR services, this was the expectation by administrators.

The Department of Mental Retardation has been successful in converting some children from Medicaid managed care arrangements to fee-for-service so that DMR is able to bill Medicaid for targeted case management. Until this occurred, once a child was enrolled in a Medicaid managed care plan, targeted case management was “blocked out” and could not be provided. DMR worked out an arrangement with the state Medicaid agency.

Home health services have continued to be an issue with the Medicaid managed care system, and among DMR eligible children is particularly evident for those with autism or behavioral problems. In general, insurance companies are not used to providing chronic care with a focus on the benefits achievable by providing services to avoid future problems.

5.5 SUMMARY OF FAMILY INTERVIEWS

We interviewed eight families in the Hartford area in the first round of case studies, during the week of September 14, 1998. Parents of these children reported that their children had had the following diagnoses: learning disability/ADHD/asthma; physical disability; developmental/learning disability/asthma; cleft palate/ADHD/learning problem; psychiatric problem; hyperactivity; developmental/learning disability/speech; growth problem/learning problem; learning disability/psychiatric problem. We conducted follow-up interviews with five of these eight families in 1999. Four were conducted during the week of October 11, 1999, and one was conducted by telephone in November 1999.

5.5.1 Experiences with the Redetermination Process

Outcome of the Redetermination Process

In 1998, five of the eight families reported that they had appealed the initial decision to terminate benefits for the child. Two of the remaining three families did not

appeal because they understood that the rules had changed and felt their children would not be eligible. The third family reported in 1998 that the child's SSI benefit had not been ceased due to a change in SSI eligibility. Instead, the family explained that the child's benefits had been suspended because the child had been residing in a juvenile facility for an extended period. .

In 1999, two of the five families that were interviewed reported that the child was currently eligible and receiving SSI benefits. These two families in which SSI benefits had continued included the family that stated in 1998 that the child's SSI benefits would be continued once the child returned home from the juvenile facility. The other three families reported that the child had been terminated from SSI with no appeal pending. None of the families stated that their child's SSI eligibility was currently under appeal.

Of those families who could not be interviewed in 1999, SSI eligibility had been ceased for one and was under appeal for the other.

Understanding of the Redetermination Process

Most parents reported in the initial and follow-up interviews that they understood that eligibility for SSI had changed, and were able to understand the letters from SSA about their appeal options. When parents expressed confusion or difficulties with understanding the process, they generally referred to how Medicaid eligibility would be handled, or to what the current status of their child's appeal was.

One family expressed confusion specifically about the dedicated account established for the child. The parent said that they did not understand why the decision not to request benefit continuation would cause limits to be placed on how the money could be spent. The parent also expressed confusion about how the money could be spent, though was able to produce the explanatory letter in the interview and could recall the specific categories of appropriate expenditures in the letter.

Another parent explained that the family would repay the overpayment (apparently incurred due to benefits received during appeal) because they had understood from the beginning that the money might need to be paid back if the cessation was affirmed. The parent recalled the specific language of the form that the family signed, regarding possible overpayments.

Appeals and Benefit Continuation Outcomes

In 1998, three of the five families who appealed stated that they had requested benefit continuation, and were continuing to receive benefits during the appeal.

One of the families receiving benefit continuation reported in 1999 that they were required to pay back an overpayment that resulted from receiving benefit continuation during the child's appeal period. This parent was paying a small, fixed amount each month. The parent, who is working, explained feeling that it was important to pay back

the money, in part because she might need government support in the future (e.g., through Social Security) and in part because it was a matter of "trust", in that she had promised to repay benefits if the child ultimately was found not to be eligible.

Of the other two families receiving benefit continuation, one was lost to follow-up due to a move out of state, and for the other family, the child remained eligible for SSI and thus no overpayment was not an issue in 1999.

One family reported in 1998 that a dedicated account had been established for the child during that year. In the follow-up interviews in 1999, no additional families reported having a dedicated account. One family that did not request benefit continuation reported that the child's SSI eligibility had been restored after an appeal, and that this resulted in lump sum payment of approximately 5-6 months of benefits but did not result in a dedicated account.

Use of Legal Assistance

None of the families reported having sought legal assistance at any time during the redetermination process. Generally when asked about use of legal assistance, the families we interviewed reported that they had never considered seeking legal help, in some cases because they did not want to incur any additional problems or get involved with lawyers.

5.5.2 Impact on Medicaid and Health Care Access

Medicaid Eligibility and Enrollment

In 1998, the child's Medicaid eligibility was reported to have been terminated in two families. Medicaid eligibility had not been restored for the child who had reached 18 years of age, by the time the 1998 interview was conducted. A follow-up interview could not be conducted with this family to determine Medicaid status in 1999. For the other child who lost Medicaid, eligibility was restored prior to the initial 1998 interview. This child lost Medicaid at about the same time that the SSI stopped; the parent explained that the social worker did not know why the child's Medicaid eligibility was affected.

Medicaid eligibility did not change for any of the other children, between the initial loss of SSI eligibility and the 1999 interview.

Enrollment in Private Employer-Based Health Coverage/SCHIP

None of the children was currently enrolled in private, employer-based health insurance. All of the children whose parents were interviewed in 1999 continued to be covered by Medicaid.

Transitions to Prepaid Health Plans

One family stated in 1998 that the child was switched to a Medicaid PHP after SSI benefits stopped. No other families reported a change in PHP status or a new requirement to enroll in a prepaid health plan in either the initial or follow-up interviews.

Access to Medical and Mental Health Services

None of the families interviewed in 1999 reported any new access problems. Neither of the families who in 1998 reported difficulties accessing health care, and who attributed the difficulties to the SSI loss—one child due to loss of Medicaid, and the other child due to what she believed was SSI (SSA) no longer paying for clinic visits—could be re-interviewed in 1999. Of those families who participated in the final interview, none reported feeling that the child's health status had declined during the study period.

5.5.3 Socioeconomic Impact

Total Income Levels

By 1999, total family income had increased for two families relative to when they were notified of SSI eligibility changes. Total family income had declined for four families. No net income changes were reported by two other families. One of the two maintained SSI eligibility and the other was receiving benefits during appeal.

Of the two families with higher net income, in one case income increased because the parent completed a training program and took a job with a monthly salary that exceeded the former SSI benefit. In another case, the family had begun receiving Social Security payments due to the death of the child's father, and this increased total family income.

Between the initial and follow-up interviews, income increased for one family, declined for another family, and remained the same for the rest of the families interviewed in the second round.

Two of the single parents reported having applied for child support in the past (prior to the SSI change). One of these parents had been receiving child support. The other was not receiving child support and did not know the location of the father or expect to ever receive child support; the social worker was reported to have said that it was not worth pursuing. None of the other single parents identified child support as a source of family income.

Work Participation

Parents in six of the families reported that they were working in the initial interview. Three of these six parents had been working prior to welfare reform, and the other three parents got jobs following the welfare reform changes in Connecticut. The parents who

had started working attributed their entry into the workforce largely to public assistance time limits at work participation requirements and in part to loss of SSI.

By the 1999 interview, a total of five families had reported an increase in working hours or a new job. The two other families interviewed in 1999 were not working. One of these two parents who were not working was an elderly guardian. The other was a parent who had a temporary exemption from the welfare reform work requirements and time limits. This parent had received the exemption due to a layoff by her employer. This parent also stated that she could apply for an exemption if a person with a disability lived in the household.

Use of Public Assistance

Of the three families that reported they were not receiving other cash assistance at the time that the child's SSI benefits were lost, one family had sought and begun receiving cash assistance for the family by the initial interview in 1998. These benefits had been lost by the follow-up interview. No additional families submitted new applications for public aid between 1998 and 1999.

Of the families who were receiving cash assistance at the time that the SSI income was lost, use of cash assistance payments increased for two families (one only temporarily) because of the loss of SSI from household income. By 1999, overall use of public cash assistance had declined for three families.

5.5.4 Caretaking and Other Child Impact

Living Arrangements

A change in child custody occurred for only one family during the study period. In this family, the child spent a period of time in a juvenile detention facility but had returned to the family by the time of the follow-up interview. No changes in household composition due to marriage or other changes occurred in the other families. Residential moves occurred for two families, including one of the two families lost to follow-up, who moved out of state in 1999.

Child Care

No specific child care concerns were mentioned by the families in either the 1998 or 1999 interviews. Those families who used child care for their children stated that they relied on family care.

Other Child Impact

One of the children was reported to not be attending school and to be "out on the streets" at night, having not returned to school after returning home from a juvenile

detention facility. This child was continuing to receive SSI benefits however. Among those who were no longer receiving SSI by the second interview, most children had seen improvements in their health status over the study period, according to their parents.

6. SITE VISIT SUMMARY: NEW ORLEANS, LOUISIANA

6.1 INTRODUCTION

Louisiana was selected as a case study site due to its high volume of affected child SSI beneficiaries and its low initial continuation rate for child SSI redeterminations. We visited Louisiana during the week of October 5, 1998 and again during the week of September 20, 1999. We interviewed a total of nine families in 1998 with re-interviews with eight in 1999. We interviewed fourteen individuals in six different agencies in 1998, and thirteen individuals in eight different agencies in 1999.

In 1996, Louisiana ranked 21 among states in the total number of children under age 18. In terms of SSI participation in August 1996, however, Louisiana ranked ninth among states in the total number of children on SSI and second in the proportion of children on SSI (at 3.1 percent). Louisiana ranked 11 among states in the percent of child SSI beneficiaries with IFA (27.2 percent of the child caseload) and 44 among states in the percent of child SSI recipients with maladaptive behavior (only 2.6 percent of the child caseload).

Orleans parish (which includes New Orleans) ranked highest among the parishes in the total number of child SSI beneficiaries, and in total IFA and maladaptive cases. Data from January 1998 on redetermination caseload status were used to select a local site. Orleans parish had the largest number of total cases subject to redetermination (2,779) and total cases ceased with no appeal (817). Orleans parish ranked lower than many other parishes in the percent completed of those cases subject to redetermination (ranked 29 of 130 parishes) likely due to the large caseload size. Orleans parish also had a low ranking among parishes in the percent of cases ceased with no appeal pending (ranked 35).

The Title XXI State Child Health Insurance Program in Louisiana has extended income eligibility for Medicaid to 133 percent FPL up to age 18 years. No state-only child health insurance program was adopted in Louisiana as part of Title XXI.

The Family Independence Temporary Assistance Program (FITAP) is Louisiana's TANF program. The average FITAP cash grant is \$155 monthly with the maximum grant for a family of three of \$190, which ranked 48th in the nation. Beginning in January 1997, benefits received count toward the time limits, which are a maximum of 24 months in a 60 month period, and a lifetime limit of 60 months. The earliest date that time limits could result in the loss of benefits was January 1999.

In the remainder of this section, we repeat the format established in Section 3, first summarizing the interviews with SSA office staff, then with Medicaid and other public and private agency staff, and finally with families in New Orleans.

6.2 SUMMARIES OF INTERVIEWS WITH SSA OFFICES

6.2.1 SSA Regional Office, Dallas, Texas

We interviewed a childhood coordinator in the Dallas Regional Office. The Dallas Regional Office covers five states including Arkansas, Louisiana, New Mexico, Oklahoma, and Texas. The Center for Disability in the Regional Office includes approximately 20 staff, which includes the director, a team leader, and two disability program analysts who supervise DDS activities. Childhood issues are handled to some degree by all of the Regional Office staff. The administrator we interviewed in 1998 indicated that there had been some downsizing, largely through attrition during the past few years.

Role in Policy Implementation

The administrator we interviewed in 1999 stated that the CDRs for children had not produced any new challenges. The general difficulty had continued in getting families to respond in a timely way. The administrator noted that each workload presented its own challenges in terms of interpreting and implementing the policies.

In terms of overall changes following the welfare reform law, the administrator we interviewed stated that there had likely been some differences in decision-making that occurred in the course of implementation, particularly around the area of mental retardation. To the extent that such differences occurred over time, the administrator indicated that they might be attributable to pressures of advocacy groups or to new training provided over the implementation period. Clarifications on mental retardation and on speech and language had been significant focus areas between 1998 and 1999. No other substantial changes to policies and procedures over the past year were identified with respect to the childhood caseload. In general, the administrator we interviewed stated that there had been high accuracy with the childhood cases across the states.

No differences across states in the region in responding to the childhood eligibility changes have been identified. With respect to differences in the impact of welfare reform on the states in the region, few differences were perceived by the administrator we interviewed.

Agency Impact and Challenges

Staffing and training. Most offices were reported to be working with the same staff levels in 1999 that had in 1999. There had been some staffing changes in Louisiana as a Prototype state (see footnote 7) mostly at the DDS level.

Overall, the redetermination process was noted to contribute to some frustration among staff because of the ongoing changes to instructions and the need to repeatedly review cases, particularly in a short timeframe. According to the administrator we interviewed, the repeated case reviews occurred in part because of the quick roll-out of

the childhood policies and procedures without all aspects of the implementation initially in place.

The administrator stated that the issue of needing further definition of the dedicated accounts policy in 1998 had largely been resolved by clarification from the Central Office in late 1998. As a result, the administrator we interviewed felt that the offices were following normal and routine procedures for this policy. SSI policy branch staff at the Regional Office continued to handle dedicated account issues including any questions that come from the field offices. Some of the payment issues that arose are related to old overpayments that the field office is unable to clear until the appeals process is completed. Field office staff continues to receive alerts about these overpayments. These payments may not be overpayments by the time the final appeal decision is made. While the field offices have received instructions about how to handle these overpayments, staff time is required to handle the alerts as they occur.

Implementation. In terms of MIS issues, the administrator we interviewed stated that there had continued to be some shortcomings with the information on the childhood redetermination cases. The specific challenge has been identifying the current status of the case. A source of these challenges has been that the whole childhood caseload has been a constantly moving target. At one time a child's appeal appears to be complete, but there may be a subsequently re-opening of the case due to good cause granted for late filing of an appeal, or due to the case being included in a rereview. Such circumstances bring the case back into the review process. Changing rules and criteria contribute to the number of affected cases. This made it difficult to capture the data on case status. Another issue is that it takes some time to enter the information and thus queries to the system might find a certain status one day and a different status the next.

The MIS issues can affect the ability of staff to know the appeals status of a case at a particular time. The MIS issues also can affect the ability of staff to determine exactly how many childhood cases have been ceased and the basis for the cessation, or how many are still pending for example,

With respect to the interface between state Medicaid programs and SSA data, the process of information exchange was reported by the administrator we interviewed as a relatively smooth process. However, Louisiana has indicated that they could not rely on the list provided by SSA of the childhood cases due to issues of incompleteness.

The administrator indicated that some issues had recently arisen with the Medicaid grandfathering provision. Louisiana has a class action lawsuit due to the way that Louisiana redetermined the Medicaid eligibility for the affected group. The lawsuit alleges that all of the affected children should have been granted at least a year of Medicaid coverage. Louisiana implemented a plan of identifying the children whose benefits were ceased due to welfare reform and had exhausted their appeal period. Families of these children received notices to come in for eligibility redetermination that were followed by several efforts to contact the family so that the necessary information could be gathered. If the family did not respond, then Medicaid eligibility might be terminated. Some were

reported to have felt that the state did not put sufficient effort into bringing the families in for continuance of Medicaid. According to the administrator, no other states in the region appeared to have had specific problems with the grandfathering provision.

In terms of medical eligibility determination for the grandfathered group, the administrator indicated that some DDS offices have procedures in place but that this has not involved the Regional Office. Most states in the region appeared to be handling this internally with the guidance from HCFA.

Caseload Status

Most of the childhood redeterminations and rereviews were reported to be completed. The rereviews had been the major activity over the past year. Approximately one hundred cases were continuing to move through the rereview process. Some of the 1996 cases may have gotten to the ALJ level at this point, but specific figures are not available at the Regional Office on the appeals status.

The CDRs have been underway with all of the CDR case processing goals having been met. All of the states in the region did postpone some of the CDRs for some period of time in the summer of 1999 because the goals were being met and because there was a refocus on the initial claims workload. This refocus on initial claims was attributed to a national effort to reduce the pending cases in all initial claims.

Experiences With Family Response and Impact

Information is not available in the Regional Office on any new applications of children who were on the rolls in 1996. This information would be available through the Central Office but those figures have not been seen recently.

The administrator indicated that there continued to be variability in the level of medical information that families have or can provide to SSI on a new claim for a child. No specific changes had been identified in the amount or quality of medical information since welfare reform.

6.2.2 SSA Disability Determination Office (DDS), New Orleans

We interviewed four disability hearing officers in 1998 and in 1999. The DDS had approximately 130 total personnel in 1998. This included 51 examiners (assigned to separate units) and 18 part time medical consultants. The examiners work within six regular operating units that are trained to work on all types of cases. There are four DHOs and one supervisor. The hearings staff were detailed (along with two hearings support staff members) to a pilot program called the Hearing Officers Temporary Staff (HOTS) that was established in October 1997 to help the disability hearings office in handling the under-18 childhood cases. This unit was expected to operate for six months.

but was then projected to last for three years. The unit was to be dissolved as of October 1999.

Role in Policy Implementation

Approximately 2,000 hearings had been completed by the staff by the time of the 1999 interview. The HOTS unit continued to handle the special caseload of reconsideration IFAs but was not involved with the continuing disability review process. The CDRs were reported as much more time consuming because they are more detailed and because there is more to evaluate. The childhood redeterminations have only required an eligibility determination based on current evidence. Because many recipients have gone many years without review, the CDRs require reviewing and citing substantial information.

Agency Impact and Challenges

Staffing and training. The last staff training on the childhood cases was reported to have taken place in Spring of 1998 and focused on the rereviews.

One staff member we interviewed reported that the redetermination process had been very rewarding and a learning experience for staff. Staff within the HOTS unit had the opportunity to actually interact with the families whereas examiners conducted paper reviews. The interaction with families was reported to provide an entirely different perspective.

The agency is now exploring having examiners meet with claimants. Initially as part of the Prototype model (see footnote 7), it was expected that examiners would do face-to-face conferences with the claimants. Some staff within the office were thought to be concerned about how well the process would work. However, the HOTS staff has been able to report not having encountered any problems in interacting with claimants. The staff we interviewed reported a very positive experience with conducting the family interviews. Explaining that there is another level beyond HOTS may have helped put families at ease. Families appeared to come to the hearing with an attitude of cooperation and honesty knowing that they are talking to the decision-maker.

Implementation. With respect to no-shows and cancellations, the trends were reported to have been fairly consistent over time. The staff we interviewed felt that these occurred for between 25 to 33 percent of all scheduled hearings. No-shows were a particular problem with one staff member having particular difficulties at the beginning of the process. The staff reported that they had tried different approaches at different times. As time went on, the staff reported making increased efforts to make contact with families prior to hearings by sending certified letters, for example. Staff stated that even with the certified letters, the families who received the letters and then responded were in the minority. The staff started conducting more satellite visits to field offices and reported that they did everything short of going to the home. While one explanation could be the location of the office, the staff we interviewed stated that they also have gone to distant locations within the community and observed the same no-show rate.

In some cases, staff speculated that the attorneys could have been encouraging the claimant to skip the hearing and to go to the OHA level. A staff member stated that one attorney reported having done this. The perception may have been that OHA would be more lenient or have different rules. However, not many of the claimants were represented by attorneys. The staff we interviewed estimated that around 3 percent of the families had legal representation. Staff also perceived that attorneys had not taken on the childhood cases unless they saw a likely allowance. Some mothers had told the staff we interviewed that an attorney had deferred taking the case after looking at it. Several of the staff perceived that many of those cases where there was an attorney involved had resulted in reversals of the original cessation. The staff indicated that this was because they were stronger cases. The attorneys seemed to be "on target" in choosing stronger cases.

The staff had seen some cases with pro bono legal aid lawyers, although the staff did not always know whether the lawyer was taking the case on a pro bono basis. One staff member felt that few of the lawyers were from legal aid. Some firms were known to have entire practices based on disability. One staff member felt that the legal aid attorneys did less screening of cases than the private attorneys. Another staff member noted that the attorneys appeared not to consider the hearings to be as important and sent a paralegal to handle the hearing while handling the DHU/OHA step themselves.

In terms of the quality of records, staff we interviewed felt that the information they had available in the childhood cases was less adequate in 1999 relative to 1998 because the information had aged. The majority of cases came in 1997 and had been sitting since that time. Staff had to do development of almost every single case and with little help. The HOTS staff generally reported that it was difficult to conduct both the examiner and the hearings officer/decision-maker functions because of the combined clerical and examiner responsibilities. Some of the staff we interviewed felt that there might have been some resentment of the special unit that resulted in the perceived inadequate support. The most significant problem identified by staff was the shortage of medical information. Normally the cases would have been sent back for development. It was thought to be more efficient to do updates within the unit than to send the cases back to the examiners. The staff we interviewed noted further that it was not the fault of the disability examiners that the cases got backlogged. The lack of support seemed to basically be due to all staff working with backlogs.

One staff member stated that in some ways the childhood redetermination process did not meet expectations. This individual thought that it was a special project and that there would be a way to expedite the cases, and thought this because of the size of the caseload that they were given.

Staff noted that about a year usually lapses between the HOTS determination and the OHA determination, and that the decisions sometimes get reversed because there is new medical information or other changes that take place in the interim. One staff member had recently heard that 20 percent of all cases that went to OHA might be reversed at that stage, but that was not specific to the childhood caseload. This did not mean that the initial decision was not correct, but instead was likely a function about the

amount of time that elapses between the decision. Several of the staff members also felt that the judges at the OHA had not had the training that they had had in the DDS, and were not as familiar with the rules. By the adjudication standards used by the HOTS team, the rationales that the judges provide do not always make sense.

The staff noted that testimony plays a large role in their decisions. Examiners do not hear the testimony and must base their assessments on written records.

One staff member noted something that was perceived as troubling, which was that in some cases the physician's assessment appeared to be generalized or stereotyped, particularly with respect to African-American culture. Dialects and also even the dress of the child contributed to what staff felt could be judgmental assessment. It was troubling because staff felt that it could influence the decision based on the information. Sometimes there also were claimants who were slow in responding or needed a question rephrased. A staff member speculated (without specific knowledge) that a physician doing the CE might not have the time to rephrase questions and instead note that someone was not cooperative. This could contribute to a negative decision to the extent that the decision-maker depended on this specific information.

Another staff member noted that there are some patterns across the physicians whose reports they see. An example was provided of a physician who was known for very low scoring that was inconsistent with other reports. The information provided in the CE does play a significant report in the decision. If the claimant saw that the information was wrong in the CE, it is possible that they can bring that to the attention to the judge. Not all but some of the staff had seen this type of pattern. One problem was that the exams are relatively short and the child often is not in treatment, resulting in little medical information. On the other hand, it was not clear why parents were not seeking help for a child who qualified for services.

According to the staff we interviewed, the volume of physicians has expanded (quadrupling during *Zebley*). Some physicians have formatted forms with content that is pre-formulated and can even be internally inconsistent. There is somewhat of a quality concern for the staff members. In cases where no treatment source has been identified a CE is required. For the redetermination caseload, few of the children had regular treatment sources. Often with behavior disorders, the child is not under medical treatment. Another explanation for the need for the CE was that some school tests are not recognized as adequate by SSA regulations.

The HOTS experience generally was reported by the staff to have made them more thorough in case evaluation. In general they reported that they look at cases more deeply and spend more time with the cases, with less effort to move the case along. One staff member reported trying to contact a potential claimant because there was information she identified that if provided, could result in an allowance. The staff felt that it was unfortunate that they would be losing some independence because they had gained more confidence in the HOTS experience. They generally felt that they had become braver in making the right decision and sending a case back if necessary. One staff member

reported a greater ability to analyze the cases with special knowledge of the childhood caseload. Sometimes colleagues come to the HOTS team with specific questions, perceiving them as experts and recognizing the specialty knowledge they had gained as well as their experience and visibility of the HOTS unit.

Caseload Status

Most of the cases were reported to be complete with approximately 100 remaining for redetermination. All of the rereviews had been completed by 1999. A backlog in the CDRs of around 500 cases was reported. Recently the CDR cases have been coming in quite rapidly because they had been on hold due to Prototype implementation and as the redeterminations were handled.

Most of the cases that were appealed would probably be at the Office of Hearings and Appeals (OHA) at this time. The staff had not seen figures on the status or on tabulations of decisions, other than their own figures.

Experiences With Family Response and Impact

One staff member noted that for the most part, the families were very honest in reporting the child's abilities. A number of the families stated that the reason that the child should be receiving disability income was because the family needed the income. In terms of the child's current treatment, families usually reported that medication was needed. The staff we interviewed stated that families had not reported much detail about how they had responded to the potential loss of income. Some of the families reported concern about losing Medicaid. In terms of benefit continuation, those families who did not request continued benefits during appeal appeared to be those who were afraid that they would have to pay it back at the end of the appeal process. Staff reported that they have asked claimants about this issue only to ensure that the claimant gets the correct letter (e.g., informing them of the decision and that payments will stop, for those who have been receiving payments).

Local Policy/Resource Trends

The staff we interviewed provided some examples of cases where a child was in need of services but was not receiving them. One staff member reported that sometimes a child qualified for social work but that the social worker was reported not to get the child from class. In other cases, it was not clear why a child had not been evaluated for special education. The staff we interviewed indicated that in general, the system of services for the children whose eligibility they reviewed was overburdened and resulted in children falling through the cracks.

6.2.3 SSA District Office, New Orleans, Louisiana

We interviewed one supervisor and four claims representatives in a district office in New Orleans, Louisiana. The district office we visited had approximately 48 employees, including a manager, an assistant manager, three supervisors, two field managers, and 40 individuals in the units (e.g., Title II, Title XVI). These staff include nine post-entitlement unit CRs, disability unit CRs, and nine service representatives. In 1998, the staffing was reported to have been largely unchanged since 1996 although attrition had resulted in a small decline in staff.

Role in Policy Implementation

The claims representatives continued to work on the redetermination cases in 1999. The workload increased for the cases under appeal in terms of interviewing and paperwork.

Over 1,000 CDRs have been done in the office, including regular disability reviews for adults, childhood, and age 18 cases. During the past year, the whole office had been working together on this process, which used to be handled largely in the SSI unit. The staff we interviewed indicated that this probably would continue in the upcoming year as well. There was a moratorium on CDRs in the whole region. While the office had started again with these cases at the time of the 1999 interview, there were some limits on the volume due to Louisiana implementing Prototype.

Agency Impact and Challenges

Staffing and training. Approximately six staff members were lost to attrition over the past year. The loss to attrition included one fewer claims representative and a number of service representatives. The staff we interviewed stated that more staffing would have made the implementation easier. The office has not been able to replace the people that they lose through attrition.

Implementation. One claims representative noted the mobility of families and felt that communication with families was a continuing challenge. There are many families who move; one CR estimated that about one-third of new claimants move within the first three months. Some families have beepers because of the address changes.

Overall, the change has had a big impact on the number of people coming into the office. The interviews also are significantly longer than in the past. For example, there used to be a single interview form and now there are three, which adds time to the interview. (This change occurred after the disability rules changed for the childhood cases.) The CRs did not feel that quality had suffered but that the time that it takes generally had increased. One CR felt that some of the forms had redundant questions but that they still had to work through all of the questions with the families.

The field office has not done anything with the treatment requirement. One CR did note that once the family files a claim, the need for medical records stimulates parents to try to find help for the child.

In terms of overpayments, some of the families have been asked to pay back funds. The initial letters were just being sent out at the time of the 1999 interview and explanations were also provided to families. One CR noted that the response from families has either been no response or a response that there is no way the family can repay the money. Families usually were requesting a waiver of recovery. If the amount of the overpayment exceeds \$2,000 then a supervisor must review the case before a waiver can be granted, and most of the overpayment amounts so far had exceeded \$2,000. The issue of repayment has only recently become significant as the appeals process has moved forward. The CRs noted that sometimes the supervisor suggests that they waive part but not all of the amount, and identify the proportion that should be waived. In many cases the child's income may have been the only income in the family. If the family is receiving AFDC they likely cannot afford to repay the overpayment. Even if the parents were now working, they might still not have significant income. One CR stated that she has one family who is paying back an overpayment with a regular amount monthly. This was perceived to be the exception. Another CR felt that the only way that the money will be recovered in these types of overpayments is if the family is still receiving support from SSA and the money can be withheld. This applied to all cases, not only to childhood cases, and applied to overpayments regardless of the type. Overall, the CRs indicated that payments would be rare except for families that were currently receiving a check from which SSA can withhold funds. If the family re-applies, then the funds can be withheld. The overpayment information stays on the record with the collection suspended, so that if the person goes into a benefit status later on, this information will remain on the record. After pursuing the case for a time, staff would file a suspension of collection.

There have not been many requests for waivers because so far most families have not responded. The CRs felt that most overpayments under \$500 are waived. For cases overall—and probably for adult cases more than for childhood cases—one CR reported that the waiver requests tend to come when the family or beneficiary receives a letter from the IRS stating that tax refunds will be withheld. At this point the office is contacted and the waiver request is made. This has been a more recent phenomenon for the SSI program.

Some of the CRs felt that there had been some confusion about the exact criteria for waiving the overpayments. There is a gray area in terms of whether a claimant may be at fault or not at fault in terms of how the claimant pursued the appeal. More clarification would always be helpful in this area. A clause in the statement refers to whether the family/beneficiary is using the money for food and shelter. Some of the overpayments are quite large, and none of the CRs wants to automatically waive such large amounts of money without consideration. One CR perceived that the different CRs probably deal with a waiver request slightly differently. The CR also felt that it might be most effective to write off the overpayments because chances are that families are going to use money for

food and shelter. However, many people might be upset if they found that all of the waiver requests had been granted.

The office periodically received questions about Medicaid eligibility of SSI beneficiaries from the local welfare office for childhood as well as for adult disability cases. The staff members we interviewed did not perceive that the volume or periodicity of these types of questions had increased since welfare reform. The CRs we interviewed did not feel that they received questions frequently from other agencies about the appeal status of a childhood case. None of the CRs had had any staff from Medicaid or from the Office of Family Support call about the SSI status of a child. The CRs noted that those offices generally use their computer interface. They also reported that sometimes a caseworker sends a family to the field office to clarify why the child had been eligible and then lost Medicaid. This was reported as an infrequent occurrence for families. The reason given was that usually the family whose child is ceased for one or more months comes to the field office because of the income loss. Staff also felt that such questions could generally be answered by a computer check.

The claims representatives have approximately 700 cases that they have to interview for CDRs at this time, for this ongoing caseload. The office put the process on hold temporarily because the DDS could not handle the full amount, given that Louisiana is a Prototype state.

The CRs reported spending a fair amount of time on the age 18 cases, but no specific challenges have arisen. They are easier than the regular cases in terms of paperwork. The staff also reported that this age group seemed to appeal the cessations at the same rate as other groups. For both CDRs and the age 18 cases, it is unlikely that there are adequate medical records. Children may have regular pediatricians but little else. The CRs noted that sometimes the IEP is available from the school but there are no records of outside medical care, except in the most severe cases. The CRs perceived that parents somewhat rarely take children to physicians when they have behavioral or mental health problems. This may be in part because parents don't know where to go for help. Some of the parents seem to be overwhelmed that they have a child who has certain problems. In some cases, a parent may not have the wherewithal to find the kind of help that they need. One CR noted that there were not many resources in mental health for children, and that even the adults are getting relatively minimal services due to cutbacks. Another CR felt that there might be unique issues for young adults because those who receive therapy and other services as children may continue to receive these services as they are part of the system, but getting into the system can be difficult, and there may be a lot of in-and-out use of the system.

Additionally, one CR noted that to gain access to physicians who care for children with mental health problems, the parent would need to get a referral from the schools or get referred in some way. Occasionally parents ask the CRs where they can go.

Dedicated accounts. The CRs have some dedicated accounts, but the volume has been relatively small. Most claims were processed within three months or fewer, and

dedicated accounts are only established for more than 6 months in back payments. The CRs stated that they always instruct the family about how to use the dedicated account and explain that the funds are supposed to benefit the child. The CRs felt that the parents understand how they are supposed to use the funds but that they rarely use the funds in the ways that they are supposed to use them; families use the funds for the household and for general family needs, along with other needs of the child, in many cases. This is not technically misuse but it also probably is not technically compliant, according to the CRs we interviewed. The CRs noted that families are faced with other needs and that it is hard for families to use the funds in such a targeted way. There are gray areas where there is a connection to the child's impairment, but the CRs noted that general improvements to the household generally benefit the child and thus there would be a connection.

Caseload Status

The CRs have not seen many cases past the hearing stage, or at the Appeals Council level, but would not necessarily expect to know the status of these cases as only a subset come back to the field office.

In terms of the types of new cases, the CRs that we interviewed had not observed any specific changes in the types of new claims being filed for children.

Experiences With Family Response and Impact

For the most part, parents asked for benefit continuation. The few who declined benefit continuation and gave a reason stated that they did not want to have to pay back the money. One of the CRs stated that she has told parents on occasion that they could continue to receive the money and put it in the bank, but did not know if any of the parents had done this. Of those who do continue the benefits and give an explanation, many have indicated that they will work it out later if there are overpayment issues.

The CRs felt that there had been a significant number of re-applications for children who lost benefits after welfare reform. These cases would now come in as new claims as the appeals period has concluded.

One of the claims representatives stated that they have applications for Medicaid in the office and that she asks applicants for the child about other children in the family, who might qualify for Medicaid or the SCHIP expansion. The claims representative reported that if the parent stated that children had lost Medicaid, the CR would make applications to LaCHIP available to the parent. The CRs felt that most of the children who are under appeal still have Medicaid, but in general they felt that parents did not raise their child's Medicaid status as an issue or report whether they had it or not. A number of the children are not receiving treatment, and thus this issue may not come up for all families.

Overall, in terms of impact on the families, it is difficult to know how families are responding or may be affected, other than that they have tended to appeal and pursue the

cases as far as they can. One staff member noted that while beneficiaries do occasionally ask for referrals, there does not appear to have been an increase due to welfare reform.

6.3 SUMMARY OF INTERVIEW WITH MEDICAID AGENCY

We interviewed an administrator in the Medicaid program's eligibility program with the Department of Health and Hospitals. The Department of Health and Hospitals administers the state's medical assistance program (Medicaid) in addition to the SCHIP, the Maternal and Child Health Block Grant, licensing and regulation programs, the state charity hospitals, and several other health programs. Medicaid is administered within the Office of Management and Finance. Louisiana is a state that confers automatic Medicaid eligibility to SSI recipients. Medicaid coverage for low-income children extends to children with family income up to 100 percent of the federal poverty level (FPL) (and 133 percent of the FPL for children under 6).

Medicaid and TANF programs are administered in different state agencies. The Department of Social Services' Office of Family Support administers the state's TANF program, which is called the Family Independence Temporary Assistance Program (FITAP), as well as the Food Stamps program, disability determinations services, and several other public assistance programs. The Medicaid agency contracts with the Department of Social Services to perform income eligibility determinations for Medicaid.

Role in the Policy Implementation

According to the administrator we interviewed, the agency has not been able to secure medical information from SSA for future disability determinations for the grandfathered group of children. The state has been trying to determine for this group of children whether they continue to meet the disability criteria in place prior to the welfare reform changes. The agency received a letter from HCFA indicating that SSA might furnish Louisiana with such information (e.g., archived records). There had been communication between the Medicaid agency and the DDS offices and also with the SSA Regional Office in Dallas about this issue.

The agency has not reviewed the child's disability status in the first year. After a child loses eligibility for SSI, the agency reviews the case and determines whether the child is in the protected group. Then at the first redetermination after one year, the agency has attempted to have the caseworkers secure as much medical information as possible. The agency does not pay for securing medical information unless an individual has no medical records available. If medical records are not available and the individual does not have other means for getting the exam, then the agency may authorize a family practice exam. The administrator we interviewed noted that it is difficult to get medical records from doctors such as those who perform SSI exams.

The agency uses the pre welfare reform eligibility criteria for disability which included post-Zebley changes, and uses any medical information that is available. The agency asks the individual to sign release forms so that records can be procured from

clinics or from other providers. They generally have good access to the "charity" hospitals, where there are sliding scale payment systems. Many of the children have been served at these facilities. In some cases the physicians want to charge for the records. However, the state does not have the funds to pay for copies of past medical records.

The same contract physicians at the DDU unit are now doing the determinations based on the information that is provided by the parish offices. There was only one physician (who is well versed in post-Zebley) working for the Medical Eligibility Determination Team at the time of the 1999 interview as one physician recently retired and another was in training. These physicians have been provided with all of the information about how to assess disability.

Louisiana implemented LaCHIP (as of approximately November 1998) as a Medicaid expansion program at 133 percent of the poverty level and expanded to 150 percent as of October 1, 1999. While is part of Medicaid, outreach is different under this program and has been quite significant. Many children have enrolled under the program. This enrollment has included children who meet pre-existing Medicaid criteria as well as children who meet the SCHIP eligibility criteria. The state has enrolled the volume of children that they expected to enroll and has recently exceeded the initial expectations.

A number of families are reaching the 24 month FITAP limit. The requirements were more restrictive than what the AFDC requirements had been. Medicaid eligibility redeterminations are performed for children losing TANF as well as for those who lose SSI. As described in 1998, the agency reviews any benefit terminations to see if the individual meets any other Medicaid program eligibility. There is a one-page redetermination form that is automatically sent to a family and the agency uses a screening program. If the agency cannot make a determination, an advance notice is sent to the family providing an opportunity to appeal, prior to any case closure.

Agency Impact and Challenges

Some specific problems have arisen for the children who are losing SSI or appealing terminations. The agency has gotten poor information from SSA on children's SSI eligibility. The problem has occurred around the child's appeal status. The state agency is now being sued in a class action due to redetermination issues for this population. The administrator noted that some of the eligibility workers were holding cases and not acting when there were appeals, and they had since been instructed to follow the appeal information. The problem has been limited information that the state Medicaid program can access that indicates an appeal. The state has been trying to determine eligibility (using the redetermination form) for children who were identified on lists from HCFA as having been ceased. It has been determined that a number of children on the lists are still drawing SSI payments. This indicates problems with the information that is available to the state.

The administrator we interviewed felt that SSA should be able to generate a list of children who have been ceased, and should be able to indicate at what point in the appeals

process the termination has occurred for a child. Eligibility workers have been instructed to make queries about appeals and to make a telephone contact to SSA, prior to making a termination for any SSI closure. This policy was in place even before the childhood caseload began. However, it appears that they may not always receive the most current information in terms of the appeals status. This generally has involved a contact between the relevant local offices.

The administrator also noted that if a child was in the affected group, but then did not meet income eligibility and subsequently family income dropped so that they met financial eligibility, then the child would be considered part of the affected group. This is different from the initial policy (prior to approximately March 1998 when a HCFA letter was issued) that the child lost affected group status once they lost financial eligibility.

Impact on Children's Medicaid Enrollment

Because so many children have appealed the SSI cessation, and others were added to the TANF grant, the administrator we interviewed in 1998 felt it was unlikely that many have lost Medicaid benefits. The administrator felt that many families had not responded to their Medicaid closure letters, however. While the agency has built protections into the eligibility determination system, having specific protections in response to legal advocacy efforts also has created more defined provisions for case handling that caseworkers must follow.

The agency has tried to generate figures on any changes to Medicaid eligibility for the cohort of children affected by the welfare reform changes to SSI. Many of the parents of these children have wanted to get the children onto FITAP when SSI is lost. The agency does send letters to the family asking them to inform the agency of changes in what the child is receiving, such as changes to FITAP status, so that the agency can look at the child's eligibility as an affected child. The cohort of children can be separately identified in the new information system that the agency is putting in place. If families do not complete the determination forms, the child could be certified in the poverty eligibility group. If the family does not submit the form, then the child could be in a poverty level group like CHAMP, or could be in the FITAP eligibility group.

6.4 SUMMARIES OF INTERVIEWS WITH OTHER AGENCIES

6.4.1 Office for Citizens with Developmental Disabilities, New Orleans, Louisiana

We interviewed two administrators in a regional office of the Office for Citizens with Developmental Disabilities. Eligibility for young children 0 to 3 years of age is based on eligibility for an early childhood program called Child Net. This is an early intervention program for children who have or are at risk for developmental delay. Criteria include developmental delay, speech impairments, and medical conditions, among others. Referrals are made through the local school system and also come from hospitals or from family self-referrals. Any child eligible for Child Net services would also qualify for

OCDD services. Once a child approaches age 3 years, then OCDD goes through a process to determine whether the child meets the state guidelines for OCDD services.

Response and Observations of Policy Impact

The administrators we interviewed stated that there had not been a significant role for the agency when the welfare reform changes to childhood SSI initially took place. Other welfare reform changes had had an impact on the agency, however. There have been issues around child care as more parents of children receiving services through OCDD join the workforce or begin training for work. This has resulted in more requests from parents for help with child support. OCDD facilitates child care for children who are receiving OCDD services. The families find the child care arrangement and OCDD provides reimbursement for the services. One of the large contracts is with a child care agency that works with the family. Generally for the children zero to three who participate in the early intervention program, the families are encouraged to place the child in a regular child care arrangement, with other children without impairments.

Observations of Family Impact

In general, the administrators we interviewed observed that most of the children receiving OCDD have been unaffected by the SSI changes because they have quite significant impairments. The population of children zero to three years would be the population that could be affected. However, the administrators we interviewed did not have any figures on how many children might be affected.

The administrators were asked about recent service system changes that might affect child SSI beneficiaries and about the possible impact of SSI loss for children in the early intervention programs. The administrators reported that as of December 1, any individual under age 21 years who is receiving Medicaid will have a case manager/personal support coordinator, based on a phase-in process. Contract case management agencies will provide these services. This is a state change, and the case managers will help families in accessing different types of needed services. This is expected to create a demand for services and to have a significant impact on delivery of EPSDT services specifically, as well as other services.

In terms of potential effects, if children lose Medicaid, then they would be at risk for losing EPSDT. A major issue for children who are receiving OCDD services and have medical or physical support requirements of some kind continues to be transportation, even though New Orleans has a good public transportation system.

The administrators we interviewed stated that families may not tap into all of the services that may be available to them after they lose SSI income. Part of the OCDD mission has been to help inform the community about the types of services for which children and families are eligible, but many of the affected children may not get to OCDD given the eligibility criteria. There are school staffing constraints that can have an impact

on children's referral to Child Net services, particularly given the volume of families referred for assistance that are received by schools.

6.4.2 School Social Work Services, New Orleans Public Schools, New Orleans, Louisiana

We interviewed an administrator in the School Social Work Services, in the New Orleans Public Schools. This department includes both Social Work Services and Child Welfare and Attendance. There are 126 schools in the system with approximately 79,000 children. The New Orleans Public Schools are currently undergoing a transition and have a relatively new superintendent (now a CEO position) and new cabinet and rearranged administrative structure.

Roles for Children with Disabilities

The social work department currently employs approximately 88 social workers, and 80 of these social workers are clinically certified. These staff serve all 126 schools. These staff primarily see themselves as brokers of resources. As a result, it is important that the department and the staff collaborate with all other agencies. Some of the agencies include family services, substance abuse, Covenant House, the charity hospital system, community services, and the New Orleans Police Department. These collaborative activities have to do with children's behavioral issues as well as with issues of attendance and truancy. Specific child welfare issues that the social workers work on are related to school attendance as well as with connecting families to social services.

In terms of roles related to children with disabilities and SSI eligibility, school staff is quite involved in assessing children's needs. Many of the SSI referrals come from assessments that are conducted of students who have problems by the Student Assistance Teams, which include principals, teachers, nurses, and potentially other staff. Psychological services are provided directly by staff through individual and group counseling. There is a psychologist on staff who evaluates children in crisis. There also is a medical services department that serves as a link for children with medical care such as immunizations. Issues for children who have mental health problems or disabilities also are handled in a separate department (Exceptional Children's Services, which is the former Special Education department). This department performs assessments and evaluations.

There is a standard referral form for teachers or administrators to use, and the social workers provide support for teachers and staff. Over the last few years, contacts with teachers have increased significantly. Due to better education and the in-service programs, the department has made a big push in the past year. The administrator felt that the school system had a good plan of service with in-services provided to school faculties each year on mental health, abuse and neglect, monitoring of truancy and tardiness, and other topics.

Response and Observations of Policy Impact

The social workers have had many requests from parents for services or referrals. These requests include SSI-related requests from parents for what the parents often refer to as "crazy checks". The administrator noted that the influx of requests for SSI came because families were in need of money. The families brought the applications to the schools. The administrator observed that in many cases the teachers did not want to handle the application and would refer the families to the school social worker. The administrator noted that in some cases, ethically the school staff had difficulty with what parents might ask. In some cases, parents appeared to be using any type of behavior problem, with requests not limited to true emotional, physical, or mental problems that the child was experiencing. The administrator we interviewed stated that these requests had diminished significantly over the past few years as changes in SSI eligibility for children and welfare reform took effect.

The administrator also noted that in general, welfare reform (both TANF and SSI changes) has created a higher workload for the department. The workload increase has little to do with the process of SSI redetermination and the need for records from the school for the redetermination process, according to the administrator we interviewed. Requests for documentation appear to have declined overall, as individuals drop from SSI and welfare eligibility.

Local Policy/Resource Trends

Both welfare reform and changes underway in the school system have had a significant impact on the schools. Overall, the stress has been relatively high among staff due to the challenges of the school reforms. Approximately three years ago the state began a process of reform that involves structural changes and accountability including student testing.

Medicaid does reimburse the school system for some services that are provided, but only one type of service generally. Another issue with Medicaid billing comes from limitations on the number of services that a child can receive in one day so that it is important to be first in submitting the claim. There may be other ways of supplementing school activities through Medicaid billing. However, in the post welfare reform days, a number of children are not Medicaid eligible. Recent school projections on reimbursement were off because some many children were taken off of the Medicaid rolls. The administrator noted that LaCHIP is a potential funding source.

The administrator we interviewed also noted that there were significant changes underway to public housing, with new units being built in place of older projects and significant relocations taking place, in addition to generally fewer units available.

Observations of Family Impact

While the administrator we interviewed was not aware of specific family needs or impact related to SSI changes, some general observations were provided about families who might have a child on SSI. Overall, the administrator we interviewed noted that families are not as aware as they should be of services that are available to them. Community education about available services continues to be an area of work for the social work department. Many of the referrals to the social workers come for the children themselves, or from teachers, but the administrator noted that fewer referrals come from the parents themselves.

The administrator also noted that some parents were not prepared for employment and that there was a need for schools to work with these parents as they approached permanent termination from public assistance. In some cases, this is resulting in multiple families living in the same household. There are many potential effects on family functioning and on the stress of children. There may be special cultural effects, according to the administrator we interviewed, because some families may have particular difficulty living within an extended family household.

The administrator we interviewed also felt that children are not receiving health services as they should. In many cases, parents appear to be sending the child to school for services. The administrator we interviewed speculated that this could have something to do with families being less able to take the children to physicians due to loss of Medicaid, and instead having their children come to school with the problem on Monday morning for services from the school nurse. In some cases this has resulted in the schools having to contact child protective services because the problem required immediate treatment. The administrator also perceived that there are fewer providers available to low-income families without health care coverage, with a decline in community and charity hospital care for the uninsured and with some type of payment generally expected.

6.4.3 Advocacy Organization

We interviewed an attorney with the New Orleans Pro Bono Project. The New Orleans Pro Bono Project provides legal aid services and referrals in the greater New Orleans area.

Role in Policy Implementation

The New Orleans Pro Bono Project was one of several legal aid/advocacy organizations that agreed to assist in the overflow of legal assistance requests that was expected following the 1996 childhood disability eligibility change. The New Orleans Legal Assistance Corporation was identified as the first point of contact following the policy change, with other organizations handling the overflow as necessary.

The Project also participated with other agencies in a statewide coalition when the eligibility changes first occurred. There was a significant effort to provide public

information about families' rights to appeal and other aspects of the process, which was done in collaboration with SSA and providers within the community. A local hotline was created for families who needed services.

Response to the Policy Change

In response to the policy change, the Project geared up by educating its volunteer pool about the eligibility changes and soliciting participation of attorneys to volunteer for the childhood cases. The project worked on getting these volunteers "engaged" in the issue. The flood of childhood cases that was expected never materialized, however. According to the staff member we interviewed, this was a surprise because Louisiana had such a high volume of childhood beneficiaries who were affected, and because as the process moved forward, Louisiana had a high number of eligibility cessations.

By 1999, few childhood cases have come to project participants. The volunteers were recently contacted to determine whether they were experiencing particular issues or problems, but no information has come up about why the volume has been low. Just as in 1998, one private law firm has taken on a fairly large number of cases, and it not clear why families have taken this route. The attorney we interviewed has speculated that the private law firm may have attracted a larger volume of clients relative to the free legal assistance organizations because of the law firm's good marketing job regarding their specialization in these cases. In terms of what is happening to the cases, it may be that some of the cases have gone away or are just not moving through the appeals process very quickly.

6.5 SUMMARY OF FAMILY INTERVIEWS

We interviewed eight families in New Orleans in the first round of case studies, during the week of October 5, 1998. The parents of these children reported that the children had the following diagnoses at the time that they began receiving SSI benefits: asthma, attention deficit and physical disorder; emotional disorder; physical disability; hyperactivity and learning problem; asthma and behavior problem; audio disorder; emotional socialization problem; and speech and learning problems. We conducted follow-up interviews with seven of these eight families in 1999. These interviews were conducted during the week of September 20, 1999.

6.5.1 Experiences with the Redetermination Process

Outcome of the Redetermination Process

In 1998, four of the eight families reported that they had appealed the initial decision to terminate benefits for the child. Four families stated that they never appealed.

In 1999, one of the families reported that the child was currently eligible and receiving SSI benefits. Five families reported that the child's benefits had been ceased and had no appeal pending (another family reported termination with no pending appeal in

1998 and was not re-interviewed in 1999). One family reported that the child's case was still under appeal.

Understanding of the Redetermination Process

Most parents reported in the initial and follow-up interviews that they understood the letters and the other information they received from SSA about the new eligibility requirements and the redetermination process. One parent (whose child's SSI eligibility was restored) reported having looked at the child's file at a hearing and not seeing a letter from the child's current provider. Those parents who expressed any confusion about the redetermination process were those who had not heard anything about the case status since filing an appeal. One parent reported that the hearings officer had actually helped the parent to see some activity limitations in the child that the parent had not known about.

In 1999, several parents provided explanations for why they had missed a scheduled appointment or had not responded in some other way. One parent reported missing an appeal in the past year for another child she was applying for, due to having another appointment at the time, and reported not having rescheduled the appointment. The parent did report knowing that cab fare was available to and from the SSA appointment. Another parent said that the child's hearing for the second appeal was missed because one of the (separated) parents did not have a phone and this resulted in confusion about who would attend the appeal.

Appeals and Benefit Continuation Requests

In 1998, three of the four families who appealed stated that they had requested benefit continuation and were continuing to receive SSI benefits during the appeal. In the follow-up interview, the fourth family reported that they requested benefit continuation. None of the families had received dedicated accounts (all were continuing to receive benefits during appeal).

In 1999, one of these four families reported that the child was continuing to receive benefits and that an earlier cessation had been reversed. One of the families was still pursuing an appeal. In the other two families, the child's SSI had been ceased with no appeal pending.

One of these two families, both of whom requested benefit continuation and lost their appeals, reported that they had not heard anything about repaying the benefits received during the appeal period. In this family, the parent was receiving SSI and not working. In the second family, the parent reported having filed a waiver of the overpayment. This parent stated that the waiver had just recently been denied, because the reasons provided for the waiver were "not good enough", but the parent was not able to explain more about why the waiver request had been denied.

Use of Legal Assistance

In 1998, one of the four parents who appealed reported having sought legal assistance. (This parent reported that a hearing officer informed her that she could ask for legal help/representation). In the 1999 follow-up interview, this parent reported trying to get a lawyer three times. This parent reported first trying the "state-appointed" lawyer and being turned down, then approaching a private lawyer who turned her down (stating that she did not have a case), and then finally trying legal aid. The parent did not know why but stated that legal aid also declined to represent/help the family. SSI benefits ultimately were restored to this child in 1999.

Another parent reported in 1998 having sought legal representation for another child for whom she was seeking SSI, but not for the child who had lost SSI benefits. By 1999 the parent had not actually sought legal assistance.

In 1999, the family of the child whose SSI was ceased and had received benefit continuation, and also had a waiver request of the overpayment denied, reported that the cessation letter said that they could get a lawyer, and that the family now had a legal aid lawyer. None of the other families had considered seeking or had sought legal assistance.

6.5.2 Impact on Medicaid and Health Care Access

Medicaid Eligibility and Enrollment

In 1998, parents of three of the eight children stated that the child had lost Medicaid eligibility after the initial cessation of SSI benefits. One child did not have Medicaid coverage due to a pending (but not yet finalized) divorce, with the absent father's income counting toward household income. (A follow-up interview could not be completed with this family). A second child had had Medicaid restored as of 1998, after the parent visited the welfare office. The third child (whose family did not appeal) had reached age 18 and was without Medicaid in 1998 and did not have Medicaid coverage restored in 1999. This family experienced a significant household income increase between 1998 and 1999, and the child was receiving private health insurance through the parent's employer.

In 1999, an additional parent reported brief problems with Medicaid eligibility; the parent was unable to get a prescription filled when the card was "swiped" and did not indicate eligibility. The reason as explained by the case worker was that the child's birthday had been entered incorrectly. More recently, the parent reported being told by the dentist that the child's card was invalid, at the time of the visit.

In 1999, one other family reported a period of ineligibility. This working parent stated that Medicaid eligibility stopped for a period of time, around the time that SSI benefits stopped (during an appeal period). The parent stated that she then enrolled the child in a different (unspecified) program and then in KIDMED, which is Louisiana's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, so the child was now covered. The parent was not sure why the Medicaid had stopped, and had not had

work or income changes over this time period although the child's SSI eligibility was on appeal throughout the time period. The parent did not report contacting an eligibility worker to find out why the child's Medicaid status had changed.

Another parent noted that the child who had received SSI was the only member of the family who continued to be Medicaid-eligible after the parent began working. This parent had the option of enrolling the children in employer-based health insurance.

Enrollment in Private Health Insurance/SCHIP

In 1999, one parent reported that the child (who was over 18 and no longer covered by Medicaid) was insured through the parent's employer-based health coverage. Due to the expense (approximately \$200 per week for the parent and two children), the parent planned to explore KIDMED as an insurance option for the children. Household income had increased significantly since 1998 (and since the SSI loss) for this family.

None of the parents specifically mentioned Louisiana's SCHIP (LaCHIP) as a health insurance option.

Access to Medical and Mental Health Services

In 1998, two of the eight parents reported changes in access to medical and mental health services following the SSI eligibility changes. Parents in each of these families attributed the access problems to loss of Medicaid eligibility. One parent sought help from relatives to pay out-of-pocket for necessary medication and physician visits. By 1999, this child had private health coverage. The other parent who reported problems in 1998 felt unable to have the child seen by a psychiatrist, and reported being told by a physician that the child could get back into the more intensive care received as a young child if there was an effort to move the child to an out-of-home placement.

In 1999, two other parents reported access problems related to Medicaid specifically. One parent reported intermittent problems with the child's Medicaid card not "working", resulting in a delayed dentist visit and a prescription (Ritalin) not yet being filled into the new school year. This parent had reported not giving the child Ritalin in the 1998 interview because a teacher said it made children into "zombies". The other parent stated that the brief interruption in Medicaid eligibility had caused postponement of a physician visit, but no other problems or impact on the child.

6.5.3 Socioeconomic Impact

Total Income Levels

In 1998, total family income was reported to have declined for six of the eight families. In two families, total family income had not changed significantly because they were continuing to receive the SSI benefits during the appeal.

In 1999, total family income was reported as lower relative to pre-welfare reform for four families (a fifth had an income decline as of 1998 but could not be re-interviewed in 1999). Income increased for the other three families. In one family, the parent began a higher paying job and also got married; in a second family, working hours increased and the SSI was restored; and in the third family, the parent began a higher paying job and began receiving Food Stamps.

Between the initial and follow-up interviews, income increased for two families and declined for a third family (who lost unemployment and then the SSI benefits paid during the appeal).

In 1998, none of the parents, all of whom were single, reported that they were receiving child support at the time of the interview. Two parents had tried to apply for child support after losing the SSI income. The other parent who visited the child support agency said that she was told that because she was not receiving cash assistance (welfare), the agency could not help her get child support. None of the families was receiving child support in 1999; the parent who felt she could not get assistance from the child support agency also explained that child support payments were accruing as debt from the father.

Work Participation

The parent in five of the eight families was working before the SSI eligibility change occurred. The three parents who were not in the workforce were either receiving Social Security (one parent) or SSI (one parent) or physically unable to work due to a recent illness (one parent).

By 1999, six parents were in the work force. This increased from five families in 1998. . In 1998, one parent reported having increased working hours after the SSI eligibility change. The other parents were working full time and did not increase their working hours or take on another job in response to the potential loss of SSI income. By 1999, a total of three parents had increased working hours or had newly entered the workforce. Thus between 1998 and 1999, two additional families had increased working hours or had newly entered the workforce.

Use of Public Assistance

In 1998, four families reported that they sought to obtain or increase their allotment of Food Stamps. At the time that their SSI income was first threatened, only one of the eight families was receiving any welfare income (and one grandparent was receiving foster care payments for her other grandchild, who was not receiving SSI). None of the families reported that they had applied for welfare since the eligibility change.

By 1999, two parents who were not receiving public assistance when welfare reform began had started to receive Food Stamps. One parent started receiving Food Stamps but shortly dropped the Food Stamps because the amount did not seem significant enough.

6.5.4 Caregiving and Other Child Impact

Living Arrangements

In 1998, five of the eight families interviewed reported changes in living arrangements. In one of these families, there was a custody change in which the child moved from one parent's household to the other parent's household. The other of these five families had moved since losing the SSI income. Three of the four families who moved reported during the interview that they had changed residences due to the income loss.

By 1999, a second (but temporary) living arrangement change had taken place for a child who spent several months in a juvenile facility, and a third child also was in a juvenile facility. Since the welfare reform change, there were household composition changes in four families (due to divorce, to marriage, or to an additional family member moving into the home). Four of the eight families moved at least one time since the welfare reform change.

Child Care

In 1998, only one of the families with young children reported having child care difficulties. This foster grandparent reported that the child currently attended an after-school center daycare program and that it was difficult to cover the child care costs even with the income from the previous job. Moreover, the grandparent was now looking for a swing shift job that would allow her to be available for the child during more of the day, but would then not have child care for the evening. This continued to be a problem in 1999, with the child having a large number of fights followed by expulsion in the beginning school year.

Preparation for Work/Independent Living

In 1998, the parents of the two children in their teen years expressed some concerns about their prospects for independent living. The parent of one of these children felt that the situation had improved significantly by 1999, in part because of a change in residence. The teen (over 18) was now back with old friends who were in local colleges and serving as good role models. The parent planned to send the teen to live with an adult relative out of state who was in the military and also could serve as a positive role model. The parent had not yet solved a recent problem, which was that the teen had been required to leave school—with only several classes remaining—because he had reached 19 years of age and was told he needed to enroll in an adult school to complete his high school education.

In the one other case, the elderly relative of a younger adolescent did not know what his job or independent living prospects were, particularly given his learning difficulties, emotional problems, and history of involvement with the juvenile justice system. These problems were reported again in the 1999 follow-up interview.

Other Child Impact

In 1998, the grandmother of two children stated that taking care of her two grandchildren had drastically changed her life and had been unable to find the kind of help necessary. She had quit a long-term job within the past year because the job did not allow her to be available for her grandchildren when necessary during the day. In 1999, the foster care payments were quite small and the grandmother reported that she had gone through her savings. She was considering separating the children and allowing the child who had been receiving SSI to go into foster care, or alternatively having both children go into foster care.

7. SITE VISIT SUMMARY: DETROIT, MICHIGAN

7.1 INTRODUCTION

Michigan was selected as a case study site due to its high volume of affected child SSI beneficiaries, its early implementation of non-SSI welfare reforms relative to other states, and its high penetration of Medicaid managed care. We visited Michigan during the week of August 31, 1998 and the week of September 27, 1999. In 1998 we interviewed a total of nine families in addition to eighteen individuals in ten different agencies. In 1999, we interviewed a total of seven families in addition to nine individuals in five different agencies.

The State of Michigan had a 1990 Census population of 9.3 million with approximately 1 million living in Detroit. Michigan ranked eighth among states in the total number of children under age 18 (at 2.5 million). In terms of SSI participation in August 1996, Michigan ranked eighth among states in the total number of children on SSI and thirteenth in the proportion of children on SSI. Michigan also ranked second among states in the volume of child SSI beneficiaries with IFA (12,803 children or 30.6 percent of the child caseload) and fifth among states in the volume of child SSI recipients with maladaptive behavior (1,996 or 4.4 percent of the child caseload).

In 1996, Wayne County (which includes Detroit) ranked highest among counties in Michigan in the total number of child SSI beneficiaries, total IFA and maladaptive cases (3,666), and total cases subject to redetermination (5,521). As of January 1998, Wayne County had the highest rank of total cases ceased with no appeal pending (1,171). As of January 1998, Wayne County ranked lower than a number of other counties in the percent completed of those cases subject to redetermination (ranked 18 of 213 counties)—likely due to the size of Wayne County's caseload—and in the percent of cases ceased with no appeal pending (ranked 23).

Michigan was one of the earliest states to reform its welfare program, with existing welfare program waivers prior to its October 1996 TANF effective date. Michigan's welfare program does not offer transitional child care or transitional Medicaid for longer than a 12 month period for welfare beneficiaries who are no longer receiving the public assistance.

In terms of Medicaid coverage, Michigan's coverage of low-income children has been expanded through Michigan's Title XXI State Child Health Insurance Program. Income eligibility for Medicaid has been extended to 150 percent FPL up to age 18 years, and Michigan's new, non-Medicaid state program (called MI Child) extends coverage for children 0 to 18 years up to 200 percent FPL. Cost-sharing for the state employee package that is offered under MI Child applies only to children with family income above 150 percent FPL.

Managed care arrangements are required for nearly all children, including child SSI beneficiaries and those children qualifying for Medicaid under the non-cash-linked, low income eligibility aid groups.

In the remainder of this section, we repeat the format established in Section 3, first summarizing the interviews with SSA office staff, then with Medicaid and other public and private agency staff, and finally with families in Detroit.

7.2 SUMMARIES OF INTERVIEWS WITH SSA OFFICES

7.2.1 SSA Regional Office (Chicago, Illinois)

We interviewed an administrator in the SSA Regional Office in Chicago, Illinois with responsibilities for childhood disability issues for the region. The Chicago Regional Office covers six Midwestern states, including Michigan, Illinois, Indiana, Minnesota, Ohio, and Wisconsin.

Role in Policy Implementation

The childhood re-review activities involved a regional cadre (including Disability Quality Branch, policy personnel, state DDS representatives, and medical staff) that reviewed childhood cases in which the federal review found errors. If there was not consensus then the case could be sent to Baltimore, to a separate cadre. The regional cadre was disbanded in 1999 as the redeterminations were completed. This process worked so well that a similar type of process will be used for the Prototype implementation (see footnote 7) to look at any cases that the DQB determines to have potential errors. The exact medical specialties that will be involved probably will change, but the process will be quite similar.

In terms of the Medicaid grandfathering provisions, this has not been an issue with which the administrator we interviewed has been involved.

Agency Impact and Challenges

Staffing and training. In terms of specific challenges over the past year, the administrator felt that a significant area in which the regional office has provided much more guidance is around speech and language. There was a need for more policy guidance in this area, in terms of the cognitive and communicative realm, and then getting the DDS offices to strengthen their staffs in terms of speech and language pathology. This has been a national trend as well as a trend across states in the region. The strong recommendation from Baltimore is that states add these professionals. Some of the states in this region have up to four speech and language pathologists in-house; for example, in Michigan (which is decentralized) there is one in each office. There also is a person at the regional office. The intention is that these staff will be maintained.

The administrator we interviewed felt that it was initially thought that speech and language was an area that pediatricians could handle. Over time it became clear that this was a very specialized area with specialized testing that not all pediatricians were adept at doing. This stemmed from the welfare reform changes in the areas of functioning. Psychologists could handle certain issues but not others. This expertise took some time to get in place but has now been resolved.

Implementation. For a while, the filing of new applications for ceased cases caused some difficulties for centrally monitoring the caseload. The specific challenge was sorting out the appeals from the new applications. The administrator did not know the reasons for the new applications (e.g., whether the child's claimed disability on the new application was different). It was difficult because there might have been a re-review followed by a new application. It was difficult to identify cases that had to be looked at again because there were many permutations of what could have happened with the case.

Ultimately all of the cases were reviewed on a case-by-case basis. The Regional Office played a role in helping the field offices to sort out how the cases should be handled, and then in providing better data to the Central Office on caseload status. Any discrepancies between the local and the Central Office data were reported as resolved at the time of the 1999 interview.

In terms of other changes following welfare reform, for the most part the impact has been limited to working through the redetermination caseload. Many of the DDS offices are specialized. There was significant specialization in response to the caseloads. Now that the caseload is largely completed, the offices are back to seeing regular initial claims and regular CDRs for children. The training has been done broadly enough that in most cases the specialization for these cases has not continued (at the level of disability examiners).

The CDR process has been an area of focus over the past year. The childhood CDRs in particular were to be done in a timely way; the welfare reform was clear on this requirement. One aspect that has continued to be a struggle relates to responsibilities in representative payees for children. Specifically, this has to do with making sure that children are receiving necessary care. This is an area where guidance continues to be sought. The administrator felt that this is really the only area where guidance is still being worked out. It is difficult to tell a parent that a different payee will be sought because the child is not receiving adequate care. Part of the difficulty is that quality or adequacy of care can depend on regional variations. The administrator felt that at this point, there probably is not the level of comfort at the DDS level that there will be once the guidance can be clarified. It was part of the legislation but so far has not been often invoked.

Overall, the welfare reform changes have been mostly dealt with at this time, with attention now focused on the Prototype implementation. The administrator we interviewed expressed confidence that particularly with the regional cadre system, staff was very careful to handle the cases correctly. The initial concerns, particularly for cases with mental retardation, were well addressed through comprehensive reviews and through

subjecting a number of cases to review by "the best and brightest" to make sure that the correct specialties were involved. This resulted in very high quality of case handling.

Caseload Status

Most of the childhood cases, including the re-reviews and hearings, have been completed within the Region. There are a few remaining cases in the states. Most states completed the caseloads at about the same time. Any remaining appeals would be at the Office of Hearings and Appeals for an ALJ hearing, or beyond.

The administrator we interviewed reported that a number of families have filed new applications for a child who was receiving SSI in August 1996 and lost eligibility under the new eligibility criteria. There are not specific, current figures at the regional level on the exact number of cases.

Differences in Impact across States

The administrator we interviewed did not identify any particular differences that had taken place over the past year across the states, other than the differences due to Michigan implementing Prototype.

7.2.2 SSA Disability Determination Office (DDS), Detroit

We interviewed an administrator with supervisory responsibilities for the childhood caseload, in the Detroit office that handles Wayne County (one of the state's four offices). Initially, the DDS was in Michigan's Department of Education, but it now has been moved to the Family Independence Agency. Due to the high volume of childhood cases, there were no particular units that handle the childhood cases.

Role in Policy Implementation

In terms of the childhood cases, the cases for which the DDS was holding hearings last year have been completed. Some cases continue to trickle in, but there is no longer a hearings staff to handle those cases. The hearings staff began to be cut back about nine months ago, and was disbanded at the end of the summer. Regular childhood cases continue to come in.

Regular CDRs had been suspended completely at the time of the 1999 interview. The only childhood CDRs that were coming in at the time of the 1999 interview were age 18 CDRs. The remaining cases were being held or sent to other states. There has been an effort to keep the childhood CDRs going, however. It was not clear to the administrator we interviewed when the childhood CDRs would become a regular part of the caseload because of the time that it takes to get staff trained on the Prototype operations. The office probably will continue to ask the other States to continue with assistance on the

caseload as long as they can offer the assistance. The offices all hope to catch up by the end of next year.

The administrator we interviewed noted that the office has not had direct involvement with the Medicaid grandfathering provision of the BBA. The office had just taken over the state's Medicaid medical consultation unit that handles state disability and other types of disability issues. This is just beginning within the office and there is a work group that is assisting in the transition. The office has also been preparing for implementation of Prototype for the past six months.

In terms of any specific impact for childhood cases or relevance to the childhood cases, the administrator we interviewed did note that so far under Prototype they have been planning for assessing the credibility of the claimant in terms of symptoms and function. At this point, it is not clear how credibility would be evaluated for a childhood case. This was expected to be a long process of implementation.

Agency Impact and Challenges

Staffing and training. The office completed its work on the childhood caseload around the time expected. However, approximately 20 individuals had to be promoted to the hearings positions from their regular operations. Thus there had been an impact on the other cases in the office. Overall staffing had not changed significantly over the past year.

The childhood caseload had an enormous impact on the DDS when it was being processed. However, now that it is over, the DDS is back to normal. The CDRs were not expected to have a major impact on office operations.

Implementation. In general, the administrator noted that there needed to be more thought ahead of time about how changes are going to interact with each other. With the childhood cases, for example, the office was buried with cases. With the Prototype implementation, the reconsideration step for initial claims was eliminated as of October 1 whether or not the Prototype States were prepared to do this or not. Even though these changes often arise from those who are not involved in the day-to-day operations, the administrator felt that in general, the offices could do a better job in implementation if there was more planning time allowed. This was not a new issue or an issue unique to the childhood changes.

The implementation of Prototype has had some impact on agency operations over the past year. The office has off-loaded some cases to the DRS and several other places; some States are taking some cases from the DDS as well, although not as many cases as the DDS would have liked them to take. The administrator we interviewed noted that each of the ten States implementing the Prototype has received a different amount of assistance from its region, with Michigan receiving less support than others. This probably has to do with caseload and size of the Prototype and surrounding states in the different regions.

When asked about whether Prototype eventually will make things more difficult or easier with respect to the childhood caseload, the administrator reported initially being enthusiastic about the face-to-face meetings with the claimant when the claimant was not going to be allowed, as a new procedure with Prototype implementation. This new procedure that was anticipated as part of the Prototype implementation had recently been changed because of expense and because in some states that offered the face-to-face option, not everyone took advantage of it.

In terms of more specific impact for the childhood cases, it is not clear how Prototype will affect them. For regular cases, the examiner is the sole decision-maker with physicians acting only as consultants. Some will do very well with this, but the roll-out is planned for one year nationally and is a significant change without significant time for practice. In terms of whether the welfare reform experience has helped with the preparation for Prototype, this has not really provided the necessary experience because the responsibilities are quite different and new under Prototype.

With respect to any learning or knowledge changes created by welfare reform, the biggest problem noted by the administrator we interviewed was that the interpretation of the criteria kept changing. By the time the process was completed, the administrator felt that there was a significant amount of skepticism from examiners in terms of the goal of the changes and more specifically whether the goal had been to produce specific numbers in the caseload. To some it seemed that the changes stemmed from concerns that in the past some children might have been "coached" to say certain things. The administrator noted that this type of case would be obvious if it occurred because the child would report it and an allowance would not be made.

Caseload Status

Those that are still coming in as part of this caseload are those that are under re-review or are for people who could not be found initially. Many of the cases were reviewed three to four times, due to the need to re-evaluate a number of cases.

The administrator was not aware that the welfare reform changes had resulted in a change to the volume of childhood cases coming to the DDS.

Experiences with Family Response and Impact

The administrator felt that families seemed to understand that their child did not meet the criteria, but may have felt that their child was being held to unfair criteria, and that Congress or someone else was singling out their child for some reason. The administrator speculated that some parents may have believed that there were "good" and "bad" impairments based on how they perceived the changes.

In terms of families accessing legal assistance, the administrator noted that this appeared to happen relatively rarely; the speculation was that it may be because legal assistance is not something that families know much about. Families are encouraged to

file appeals if they want to do this, but little information is available on why families do or do not seek legal help.

There are some people who understand the changes to eligibility but do not see the rules applying to their own children. In the hearings, it is often clear that the child does have some type of impairment, but it is not an impairment that fits SSI criteria. Learning disability is a major area. In some cases, the administrator speculated that this may have been an area that was not well thought out when the rule was changed; these children often do not appear disabled but do have significant problems.

There is not a lot of information on what families are doing in response to the changes. In terms of whether there are new applications for the initial cohort, the DDS does not have figures on how many new applications have been filed for this group. The office does see a number of cases over and over, but if the family does not apply right away, the office would not know on any routine basis what proportion of cases are in this group.

Overall, there has been increased press regarding the state of children in Detroit. There is a fair amount of information in the news about the impact that all of the welfare reform changes are having in Detroit. Detroit continues to be one of the cities with the largest number of children living in poverty, and Michigan has been focusing on returning people to work. They are receiving minimum wage jobs but still can have lower income than when they were receiving public aid or SSI.

7.2.3 SSA District Office

We interviewed one supervisor and four claims representatives in a district office in Detroit, Michigan. The district office we visited had about eleven CRs in 1998 and did not report significant staff changes in 1999.

Role in Policy Implementation

The CRs have continued to contact some of the families in the original cohort, but the numbers have declined over the past year.

The staff generally noted that they had been lenient in the time limits for appeals etc., based on early instruction about the 10 day limit, and that they continued to be lenient. The staff reported that they do emphasize to the families that it was important that they respond in a more timely way.

The CRs noted that problems have occurred sometimes with Medicaid eligibility. There are some discrepancies in bookkeeping in terms of who is listed as being on Medicaid but not receiving it. Continuations sometimes fail in the computer system, on the state Medicaid side. The field office only knows that there is a problem with Medicaid if the family calls.

In terms of the grandfathering of Medicaid, if there are questions, the field office generally refers the family to social services. Sometimes there are discrepancies between state and SSA (field office) records as far as dates; there are cases in which SSA records show the individual as Medicaid-eligible and the individual is not receiving a Medicaid card. There is a contact person at the state in Lansing for specific problems that come to the attention of staff. This relationship works well and generally solves problems that arise.

An example is redetermination cessation cases where the family is appealing and getting benefit continuation. In many cases the computer sees the cessation but does not pick up on the continuation and terminates Medicaid. If the family does not receive the benefits card and calls the field office, then the problem can be resolved. If the family calls social services instead, they may not get anywhere because the caseworkers do not always understand the process. The staff did not know exactly where the information breakdown is in the interface system.

The staff we interviewed did not feel that there had been any increase in contact or involvement with schools or advocacy groups. One staff member noted that some schools and teachers saw the SSI payments as potentially encouraging problem behavior and thus did not expect that the schools would be calling to complain about children losing SSI. This may be in contrast to the reaction to the *Zebley* decision.

Agency Impact and Challenges

Staffing and training. The staffing had not changed significantly over the past year, but the workload has increased dramatically. Most of the workload increases are due to redeterminations and due to the limited issues, such as the wage alerts. CDRs in SSI post-entitlement are expected to be a major area of workload increase. Some cases were several years behind on the diary date due to staffing limits.

In terms of more permanent changes caused by welfare reform, the staff works on separate areas rather than as generalists, dividing CDRs work from post-entitlement work. This was implemented in Fall 1998 due in part to the childhood changes and resulting workload volume. Part of the reason was the difficulty in getting through the childhood and alien cases that came in the middle of the year. The response was to divide the units into one unit for initial claims (and related appeals) and another for post-entitlement, redeterminations, limited issues, or CDRs and overpayments. This reduced pressure on staff because staff did not have the pressure of doing everything. This was reported by the staff we interviewed to have provided staff with more control.

Implementation. Michigan received some minimal help from other states to complete the reconsiderations and CDRs while they prepared for Prototype implementation. The DDS also attempted to condense 12 months of work into 9 months so that the DDS could meet their goals for the year. This resulted in a major effort within the field office as well to get through this caseload.

In terms of overall impact, the staff noted that they had always needed to be flexible in their workloads. This was one of many recent caseloads and caseload changes. Several of the CRs noted that welfare reform in general had affected the CR workload in that many families were now working and requiring wage verification checks. The office is getting a significant volume of alerts (several hundred alerts for the quarter) for individuals for whom no income had been reported, which involves contacting the individuals. In some cases the individuals had multiple jobs that had not been reported. This is significant for childhood cases because of the significant changes in working behavior of parents. It used to be that someone on AFDC with a child on SSI would not have a yearly review because the profile was not expecting changes. However, the profile needs to be changed because there are huge changes due to welfare reform and due to the economy (and job availability). There was an increasing volume of monthly wage checks where families are required to submit documentation of earnings. Some families do not comply with this requirement, and this triggers follow-up by staff.

One staff member noted that there are new packages (as part of a pilot) that have been prepared for first-time applicants for children's benefits to provide them with more information and to make them more active and knowledgeable claimants. The staff noted that the notices and letters generally have been difficult to understand, in part because of the past court cases that require specific clarifications. The letters contain a mix of medical program information and law that is not concise and clear so that the message can get across to potential beneficiaries. As an example, a beneficiary may receive a letter of an award that also notifies the beneficiary of appeal rights. Some beneficiaries then call the field office and say that they want to appeal. Staff noted that they are operating both a medical program and a legal program. Even though improving materials has been a frequent initiative, the necessary improvements have not been made.

Dedicated Accounts. Dedicated accounts continued to be a major activity for the claims representatives. One CR noted that despite explanations about how to use the money, families appear not to understand how they are to use the dedicated accounts funds and how this differs from appropriate expenditures of their monthly payments. The appropriate uses of the funds can vary based on the child's disability. The families have provided receipts for many different things. The office has received a number of waivers and reconsiderations stemming from the dedicated accounts.

One staff member noted that the dedicated accounts policy was not well-thought-out. Due to the size of the funds, it was reported to be difficult for a family to leave the money in the account when they could use it to get a car so they would not have to take the bus, for example. The letter does suggest getting prior approval for larger expenses. One staff member felt that the policy could have required SSA staff to issue the money based on requests. The repayment rate for the misapplied funds was estimated to be very low, possibly 1 percent of cases. For funds identified as misapplied, there can be a reconsideration and then an appeals level. The reconsiderations are done within the field office (by a different claims representative). Generally staff felt that they were in concurrence about the policy, and few reconsiderations resulted in a different conclusion unless the family brought in more information.

Another CR felt that the letters could be more clear. In general, the CRs stated that they felt they were clear in their explanations and the problem was how the accounts were structured.

Another staff member speculated that part of the problem could be the "word on the street". This happened during the post-*Zebley* period as well. When the first families with dedicated accounts were told to pay back the money and did not, the field office had "no teeth" in terms of repercussions. Word of this may have spread. One CR reported recently talking to a parent who was cooperative but said she had heard that the dedicated account involved a resource limit, in which unspent money would indicate that the family did not need it with a resulting decline in their regular monthly payment. Another CR reported being told by a social worker that the dedicated account was not excluded from TANF considerations of income eligibility.

The staff reported that they were generally approved waiver requests of overpayment as long as there was a good faith effort on the part of the family. To receive a waiver the family would have to be without fault and unable to pay it back. If a family is receiving SSI they are generally considered to be unable to pay it back. If the family appealed because they feel the disability had not changed and ultimately the benefits are ceased, then this generally constitutes being without fault. One CR noted that a case that was ceased because the parent did not attend the hearing might not indicate good faith.

Caseload Status

The claims representatives felt that most of the cases had gone through the redetermination process with some possibly having reached OHA/the Appeals Council. Most cases have been through the DDS. One staff member noted that the ALJs tend to process the payment continuation cases more quickly.

One staff member noted that while many families had appealed, there were fewer appeals than she had expected. There are a few that have gone through the hearings levels and have come back as reversals (continuances).

One CR stated that when families first responded to the letters sent out about the eligibility changes, the CR explained what the changes were about so that they would understand. It appeared to this CR that about 50 percent of the families were very concerned and wanted to appeal due to the cash payment but also due to the need for Medicaid. Parents said that they might be able to find a part time job but were concerned about the child's Medicaid status. The CR also noted that when the appeal affirmed the earlier cessation, very few of the families returned. The staff we interviewed felt that possibly 60 or 70 percent of the cases involved appeals. Several CRs felt that some parents wanted to go through the appeals to see if their child would still qualify but did not necessarily expect that the child would be eligible. Health status for many children appeared to have improved (such as children who initially were found SSI eligible as low birthweight infants).

Another CR stated that for the most of the appeals, the parent felt that the child has the disability and needs income assistance as well as Medicaid eligibility. Welfare reform affected families in many ways and initiated changes to family income structure.

For the children who lost eligibility, the CRs we interviewed generally felt that there were few new applications being filed. One CR noted that there were some re-applications for a different disability for the same child, and felt that those tended not to be allowed either. This perception was based on a small number of cases.

The CRs felt that new applications occurred more frequently among the age 18 cases. Many of these cases have been ceased, and there have been some appeals. For these individuals, the field office encounters issues relating to capability determination as a legal adult. Based on inexperience, these individuals often have difficulty with completing disability reports, and with responding to letters and completing forms in a timely way. Some but not all have parents who can help them.

The office has not been performing CDRs since June 1999 due to implementation of Prototype in Michigan. The age 18 cases also were on hiatus until just recently. The office was keeping up with the CDRs before they were put on hiatus. Scheduling the visits to the office was a challenge because people did not always come on the correct day. It is like a new application in some ways and requires a significant amount of effort from the staff.

One staff member noted that there was significant difficulty in the community in terms of children accessing the appropriate services. An example that was offered was special education, which was overcrowded and not provided in some schools. This makes it difficult for field office staff to procure the necessary medical eligibility information, such as the IEP. Sometimes a child will still be on the waiting list and not yet have an IEP. Staff also noted that reviews of children with learning disabilities should not be done during the summer due to the unavailability of information from the schools. However, the review must be performed even if there is not an initial IEP or an updated IEP. Since some children could have been allowed prior to welfare reform with just CE results, this would result in very little information being available in some records.

Experiences with Family Response and Impact

In general, parents did not complain to the CRs about the loss of SSI. In many cases, the child's health status has improved over time. Some of the children who initially qualified as low birthweight infants have improved over time. The majority of the families are already receiving public aid. Some of the parents state that they are worried about keeping the income, but parents who express concern about the loss of SSI tend to state that maintaining Medicaid for the child is their primary concern.

One staff member noted that if families become eligible for Medicaid through receiving SSI, they do not need to go through quarterly eligibility evaluations for Medicaid. If they lose SSI and thus linked Medicaid, then they need to reapply through

the welfare office, which is a complicated process. The staff we interviewed felt that the family probably does not receive a separate letter from FIA explaining what will happen to the child's Medicaid. Some families might only realize that there was a change in Medicaid status when they do not receive their card for a given month.

There are other implications of the SSI loss in terms of Medicaid. A staff member noted that a child may be dropped from a prepaid health plan's (PHP) enrollment if there is even a brief interruption in Medicaid eligibility. The problem is partly that the PHPs are at capacity in certain locations. Thus if a child loses Medicaid eligibility, then disenrollment from the PHP occurs and even if the parent reapplies, the parent will receive a new application and will need to select from the PHPs that are not at capacity. It was the staff's understanding that this would occur even if the child qualified under a different Medicaid eligibility category (other than SSI) because there would be an effective break. It would also take a rapid and persistent effort from the parent to get this immediately resolved. It could take several months to resolve. This could happen for a child who has an ongoing relationship with a provider or rapport with a counselor, and it is possible that the provider does not contract with all of the PHPs. A staff member made the point that there is not a good transportation system in Detroit either, so this can be an issue especially if the family needs to change the location of care.

It appeared to the staff we interviewed that some families are filing new applications for the children who lost benefits. In some cases, the family could have appealed initially but then stopped pursuing the appeals. After a period of time without the income, these families may have decided to see if the child might be eligible.

According to one staff member, families tend to call saying that they have received a letter but are not sure what it says, and often either do not understand it or misconstrue its contents. One staff member noted that it takes a lot of stamina to keep things running smoothly in a family, and for some the families in poverty it is difficult for them to address things in a timely manner.

Another staff member noted that the SSI changes are taking place during a good economic period with a tight labor market. Thus people who wouldn't have gotten hired several years ago are now getting hired. It will be important to see whether they will be able to maintain the jobs. There are many families who have had several jobs in a year, potentially due to job skills or to not being able to work out a child care arrangement, especially for a child with significant behavior problems.

The staff we interviewed noted that families often ask about legal help. The office maintains a list of legal aid numbers that was provided to families along with the toll-free number for legal assistance that was specifically for children. In terms of getting legal help, it seemed to one staff member that many families have representation at the hearing level. It appears that the ALJ informs the family that they can have representation and given that this is an intimidating experience, the family can decide at that point to get representation. Staff also noted that this causes a delay in the hearing process.

7.3 SUMMARY OF INTERVIEW WITH MEDICAID AGENCY

We interviewed an administrator in the Medical Consultative Division of the Family Independence Agency. The Department of Community Health includes the Medical Services Administration, the Community Public Health Agency, and the Behavioral Health Agency.

Role in Policy Implementation

In 1998, the administrator we interviewed felt that there was no systematic reason that children would lose Medicaid benefits during the appeals process, or following benefit termination. The staff member interviewed in the Medical Consultative Division perceived that most of the children in the “grandfathered” group had their Medicaid eligibility reinstated. In 1998, an administrator in financial services who was interviewed had not observed any drop in Medicaid enrollment figures that would indicate that children who lost SSI were losing Medicaid coverage.

In 1999, the administrator we interviewed noted that children's eligibility for Medicaid under the grandfathering provision would not be handled within the medical consultative unit. The medical unit was preparing to be merged into the DDS. The administrator also reported that the unit has had access to SSA training on disability determination. Consultation with the DDS and with the SSI advocacy unit medical staff also occurs in some cases.

7.4 SUMMARIES OF INTERVIEWS WITH OTHER AGENCIES

7.4.1 SSI Advocacy Program

We interviewed an administrator in the SSI Advocacy Program, which is housed in the State Office of Legal Affairs. The primary function of the SSI Advocacy Program is to assist individuals who receive State Disability Assistance in applying for SSI. These individuals have qualified for Medicaid through a disability-related aid group and are required to apply for SSI.

Roles for Children With Disabilities

The SSI Advocacy Program has organized to provide representation to children, mostly those in out-of-home foster care placements, during their SSI eligibility determination. Overall it has been found to be very cost effective to identify children in foster care who may be SSI eligible. In 1998, the administrator we interviewed described a pilot program that had been developed to screen the full foster care caseload for children who might be eligible for SSI. The FIA issued a contract for the screening of children's medical records for the purposes of identifying potentially eligible children. This largely meant a tightening of current policy to screen cases for potential SSI eligibility, rather than a completely new policy.

In 1999, the interview focused on impact of welfare reform on efforts to identify SSI eligible children within populations served by FIA, and on the SSI Advocacy Program's role with children whose SSI eligibility was undergoing redetermination. The foster care pilot was underway when the welfare changes occurred. The administrator we interviewed felt that on appeals cases in the foster care population (of new applicants), only about 3 or 4 percent of cases resulted in SSI allowances. Removal of some behavioral aspects of eligibility was thought to be one reason. The administrator estimated that there had been approximately 300 cases of children in foster care who were identified through the payment reconciliation assessment process as potentially SSI eligible. A number of cases were screened out, where the staff perceived that the case had no merit, leaving around 30 or 40 cases that went through hearings and around 5 to 6 findings of eligibility.

With respect to the allowance rates for initial applications from the foster care population, the administrator we interviewed noted that as children were exposed to services, they often had improvements in functional status (behavioral problems, for example). Many of the children also may be in crisis when they initially are assessed and then improve in function over time or at least do not deteriorate.

In terms of policies in child protective services, the administrator we interviewed indicated that as foster care workers become aware of a possible disability, they notify the payment reconciliation section, which then determines what it will pursue based on the level of care and the state participation rate. The administrator felt that it was possible that there were more children in protective services who could be identified as potentially SSI eligible but explained that resource limitations precluded a broader screening process. Overall, the administrator felt that progress was being made, however. For example, it appears that there is now a more formalized and consistent approach in foster care worker training around the medical issue identification for children, including SSI issues.

There is a pending program in the FIA to screen child AFDC/TANF beneficiaries for potential SSI eligibility. Children with potential SSI eligibility were identified based on the presence of a school-based services Medicaid service code flag, indicating that they had received medical school-based services. A legal aid agency screened the cases and assisted in completing the applications. The administrator we interviewed stated that due to TANF changes in the funding formula, there was no longer funding to pay for this screening effort, although alternative funding was being explored.

The experience with the population identified through use of school-based services was that of the 300 cases that were "screened in" (with a letter then mailed to the family) and got some family response, about 60 families elected to pursue SSI. The families who responded were referred to legal aid for help with completing forms. The legal services provider appeared to have good success in keeping the families in the process, most likely because of the relationship that is established with the family. Of the 60 responses, there were about 15 allowances. While this is potentially a viable program, and the program is relatively sophisticated in terms of the screening criteria, the resources involved made it not cost-effective at the time of the 1999 interview.

Response and Observations of Policy Impact

The program has not worked on identifying potential SSI eligibles within populations other than the foster care and the FIP caseloads. The program also has not participated with ongoing disability reviews due to lack of resources. These cases are labor intensive and complex.

One issue that did arise out of welfare reform was related to dedicated accounts. The problem has to do with accepting the retroactive funds. The dedicated accounts policy has created a quandary for the state as to whether they can accept the dedicated accounts, and how the funds could be used. According to the administrator we interviewed, so far the state has not accepted these funds. The administrator we interviewed has been in contact with other States to determine how they are addressing this issue. The administrator was not aware of any other States that were accepting these funds due to the restrictions that are placed on the funds. According to the administrator we interviewed, some staff in the program felt that because the state is paying for medical care for children in protective custody, this would be an appropriate use of the dedicated account funds (as reimbursement for medical expenditures). This use of the funds has not been tried.

In terms of Medicaid eligibility, the administrator we interviewed explained that Michigan had decided to keep children on the Medicaid rolls during the appeals process. Overall, there also has been an increase in children's Medicaid eligibility due to federal changes, and this has increased the number of children enrolled in Medicaid.

In terms of lessons learned, the administrator we interviewed felt that it would be beneficial to direct resources to better identification of children, such as developing a profile to identify potentially eligible children.

The administrator also noted that while there has always been training of foster care workers around medical issues and SSI, there probably is a more formalized and consistent approach now. Staff reductions and policy changes also have been significant in recent years, but now there may be more opportunities. There are quarterly meetings to address issues of disability and SSI with attendance from the DDS, community health services, education, and the SSI Advocacy Program, among others. This has been a useful forum with information exchange.

Observations of Family Impact

The administrator we interviewed noted that welfare reform has reduced the SSI eligible population but also has contributed to parents feeling that it is not worth applying for benefits for the child. Both of these effects may reduce the numbers of children found eligible through the screening efforts of the program.

7.4.2 Michigan Protection and Advocacy Services

We spoke to a staff member of the Michigan Protection and Advocacy Services (MPAS) based in Lansing, Michigan. Protection and Advocacy has a \$3.6 million annual budget. Attorneys with MPAS provide legal representation and legal counsel to eligible persons, and also provide legal technical assistance to private attorneys who work on disability issues. MPAS also provides training and seminars in Michigan on legal disability issues. Specific programs operated for children with disabilities include the Advocates Supporting Solutions in Education (ASSET) network program that trains parent volunteers on advocating for children with disabilities, and for their children in special education. MPAS also operates the Michigan Self-Help Clearinghouse that provides workshops and training to many Michigan groups and national organizations.

Role in Policy Implementation

Protection and Advocacy started to participate in the childhood SSI issues when the American Bar Association became involved. Protection and Advocacy volunteered to provide the hotline, which would send families who called to the legal aid in their area, beginning in October 1997. If a family returned from legal aid to Protection and Advocacy, then representation was facilitated for them.

When a number of families lost benefits in early 1998, there were a large number of calls. There was another large volume of calls (possibly several hundred) around the end of the year as a round of hearings took place. The staff member we interviewed did not know how many of these cases resulted in representation.

Part of the office's role has been to supervise referrals to legal aid or to private attorneys; one concern has been that families need representation but do not follow up in all cases. Another problem has been that families who do call often call at the last minute. In general, DHOs appear to provide extensions in this situation without much difficulty. According to the staff member we interviewed, it is said that some DHOs may require an attorney to agree to take a case before being allowed to view the files. Some attorneys may take the cases based on the information available.

Another challenge has been that a number of the families have trouble keeping records and knowing exactly what is happening with their child. This can pose a challenge to attorneys working with the family. Families may not know what the current medical situation is or what school programs the child participates in, for example. In those families who have called about SSI eligibility for their children, the parents often appear to have more difficulty understanding the process or with organization in general compared to many others who call the agency seeking legal assistance.

In general, the staff member we interviewed noted that it can be difficult to get private attorneys involved in these cases because the families have no money and there is little chance of attorney fees. In terms of involvement of private firms, even the lump sum

payments for children would be relatively small. There has been a fair amount of pro bono activity.

The staff member we interviewed also stated that in some cases families may be told at legal services that they will not take the case until the hearing level. This happens because of the lack of resources. Generally involvement begins not much earlier than the ALJ level, although the staff member we interviewed felt that it might be productive for the families to have representation/legal assistance earlier in the process.

The staff member also noted that Medicaid benefits were being terminated in some cases. This appeared to be a local office problem in which the social services case workers were not sure what to do. If families called the legal aid organization about a loss of Medicaid, they could get advice on what to do. Attention has been focused on this problem, and there have been administrators in the state Family Independence Agency who have worked on this problem. There has been input from others including the legal assistance community into the FIA efforts to rectify Medicaid eligibility problems for the affected children.

Observations of Family Impact

The staff member noted that the changes to children's SSI eligibility may have had special impact in low-income families in the inner-city, in part because of the need for a family to have the wherewithal to respond in the eligibility determination process. The staff member reported significant concern about the continued welfare of these families, given that with the cuts, the families can "disappear" without anyone knowing their level of welfare. It is not clear what is happening to these families after the income loss occurs.

7.5 SUMMARY OF FAMILY INTERVIEWS

We interviewed nine families in Detroit during the week of August 31, 1998. Parents of these children stated that their children had the following diagnoses when they began receiving SSI: hearing deficit and learning disability; Tourette's Syndrome and ADHD/behavior problem; ADHD and learning problem; emotional problem; ADHD, asthma, and emotional problem; learning problems and enuresis; learning problem; asthma and seizures; learning problem, behavior problem, and delayed motor development. We conducted follow-up interviews with seven of these nine families in 1999. Five interviews were conducted during the week of September 27, 1999. Two interviews were conducted by telephone in October.

7.5.1 Experiences with the Redetermination Process

Outcome of the Redetermination Process

In 1998, six of the nine families had appealed the cessation of SSI benefits either when eligibility was first ceased or later in the process. Four of the six families who

appealed had requested benefit continuation, and three of these families were continuing to receive benefits at the time of the interview. The remaining three of the nine families stated that they had not appealed.

In 1999, none of the seven families who were successfully recontacted reported that the child was currently eligible and receiving benefits. Five of the seven families reported that the child's benefits had been ceased and that there was no appeal pending (another family that could not be re-contacted in 1999 reported in 1998 that the child's benefits had been ceased, with no appeal pending). The remaining two families reported that the child's eligibility for SSI was still pending an ongoing appeal (another family that was not re-interviewed in 1999 reported this outcome in 1998).

Understanding of the Redetermination Process

In 1998, all of the parents reported that they understood the letters and other information they received from SSA about the new eligibility requirements and the redetermination process. Overall, in the initial and follow-up interviews, parents who had problems understanding the process expressed confusion either about what information SSA was considering in re-evaluating their child's eligibility, or what the child's status was during the appeal.

In 1999, several parents provided explanations for why they had missed a scheduled appointment or had not responded in some other way. One parent said she did not bring her child to the last hearing because it wasn't made clear that the child should attend, and stated that she threw away the next letter from SSA but was then encouraged by her family to re-contact SSA. Another parent (who does not have a phone) said she thought that a lawyer was supposed to attend the hearing, and not the parent (although this parent did not have a lawyer), and did not recall receiving letters about the scheduled hearing, also stating that she just did not follow through with the process.

Appeals and Benefit Continuation Requests

In 1998, four of the six parents who appealed stated that they had requested benefit continuation during appeal. Of these four parents who requested benefit continuation, one parent believed that he had requested continuation of benefits for the child but was not receiving benefits during the appeal. Another one of these four parents received benefits during the first appeal period but not after a subsequent appeal.

Of the three families who received benefit continuation during appeal, two reported in the 1999 interview that their appeals had resulted in affirmation of the earlier cessation and that they were required to pay back the overpayments incurred during appeal. Both of these families had filed waivers, but had filed recently and thus did not know the outcomes of their waiver requests. In the third family, the parent had been notified of an overpayment of less than \$1,000 and also understood that there was an option to request a waiver.

One of the families had missed a recent hearing for the child and did not know whether they could reschedule the hearing. The parent explained having missed this hearing because the child was out that day with the other parent and did not arrive home in time. This parent was not working and relied only on public aid. Another of the parents was working and had not initially appealed, but did appeal after receiving multiple phone calls asking why the family did not appeal. The third family (a foster relative) had recently given up custody of the child to another relative due to the loss of SSI. Of these three families, one parent recalled being told that the chance of having to pay back benefits received under appeal was very small.

Use of Legal Assistance

In 1998, one parent stated in the interview that she felt she was discouraged from getting a lawyer when she first called the SSA office after receiving a general letter informing SSI beneficiaries about welfare reform. No other families reported considering or seeking legal help.

In 1999, one parent stated that she had called a lawyer once and was told to wait until the child's appeal resulted in another affirmation of cessation. This parent stated that by that time, she had forgotten about the lawyer. Two other families stated that they had not considered getting legal assistance but that they might consider it in the future. One family felt that legal help would create its own difficulties and thus was not considering it. In another family, the parent explained that they had lost the phone numbers for legal aid.

7.5.2 Impact on Medicaid and Health Care Access

Medicaid Eligibility and Enrollment

In 1998, two families reported that Medicaid eligibility had been lost after SSI payments stopped. Medicaid had not been restored for either family by 1999. In the 1998 and 1999 interviews, one family stated that losing Medicaid had affected the child because the private insurance that now covered the child did not provide coverage for vision services, and the child needed glasses.

Transitions to Prepaid Health Plans

In 1998, only one family reported that they might have to switch the child from fee-for-service to a Medicaid PHP. This had not occurred by the 1999 follow-up interview.

Use of Private Health Insurance/SCHIP

By the 1999 follow-up interview, three families had obtained private coverage for the child. One family had always had private coverage and never used the Medicaid benefit. In another family, the child had begun receiving coverage through the parent's work. In the third family, the parent had taken a second job so that she could secure

private employer-based coverage for the child. This family had just recently re-applied for and received Medicaid coverage for the child so that they could reduce the medical bills that the family would have to pay.

In 1998, several parents said that if their child lost Medicaid, they did not know of any other Medicaid or public health insurance options for their children. In 1999, no additional children had lost Medicaid.

Access to Medical and Mental Health Services

In 1998, several parents raised difficulties with access to health care for the child. One parent reported not being satisfied with the choice of mental health professionals in the private health plan for the child; in 1999, the parent had switched the child back to Medicaid coverage and felt that there would not be access problems once they could find an specialist in allergy. The child lost access to an allergist when the switch occurred, and the family practice physician who now cared for the child was following the health care management plan prescribed by the former specialist, while they worked to find a specialist.

7.5.3 Socioeconomic Impact

Total Family Income

In 1998, total family income was reported to not have changed significantly in three of the nine families. For two of these three families, total income had not changed because they requested benefit continuation and were still receiving monthly SSI payments for the child. In one family, the total household income had remained nearly at the same level after SSI payments ceased because the child was added to the public assistance grant and because the mother had begun working. All of the parents who had lost SSI benefits for their child reported lower incomes relative to the period when they had last received SSI.

By 1999, income was reported to be higher in two families. In one of these families, the parent was newly engaged and due to the change in the household had an extra income added to the household income. In the other family, the parent had a new job with a higher salary, and was still receiving Food Stamps and public aid (including a small amount of public aid for the affected child).

Income was reported to not have changed for one family because new earned income had replaced the lost SSI. In the other families who were interviewed in 1999, income continued to be lower relative to pre-welfare reform. Between 1998 and 1999, income increased for three families and declined for two families. No income change occurred between 1998 and 1999 for the remaining two families.

Work Participation

In 1998, the majority of the parents we interviewed had gone back to work or had increased their working hours in response to the loss of SSI income. Two of the nine parents themselves continued to be recipients of SSI.

By 1999, in the families with a working parent, three parents had increased their working hours or started working after the SSI eligibility change (including one parent who could not be re-interviewed in 1999).

Use of Public Assistance

In 1998, two of the four families with public cash grants grant at the time reported having added the child who lost SSI benefits to their grant. One family planned to apply for a new AFDC/TANF cash grant. None of the families had newly applied for Food Stamps.

By 1999, one of the families had increased use of public aid, relative to the pre-welfare reform period. This parent was working under a workfare program and continuing to receive public aid for the family. None of the families had newly applied for public assistance since welfare reform. Only one family (who could not be re-interviewed in 1999) reported a decline in public aid use between pre-welfare reform and 1998.

In one family, the child's SSI had been lost but another child in the family began receiving SSI in late 1998.

In 1998, five households were single parent households, and one of these five families was receiving child support for the child. The parent reported in 1998 that the FIA was now requiring the father to provide formal child support but was taking some money out of the father's contributions, which the mother described as resulting in less net income coming to the child and the household overall. Another parent had applied for child support in the past but had never received payments. By 1999, a third family had submitted an application for child support.

7.5.4 Caregiving and Other Child Impact

Living Arrangements

In 1998, the grandmother in one family had temporary custody of four children under age 15, two of whom had been receiving SSI. The grandmother said that she planned to request permanent custody in the near future because her daughter would never be able to take custody again, but that to maintain custody she needed extra resources to make sure that the household was adequately maintained for the children. By 1999, the children had left the household with custody transferred to relatives in the two different households in which they were living. There were no custody or caregiver changes in the other families who were re-interviewed in 1999.

Other than the family with the custody change, by 1999 there were changes to household composition in two families, due to an engagement (one family) and due to a divorce (one family). One of the families moved between 1998 and 1999, with no other families re-interviewed having moved since the child's SSI was initially affected.

Child Care

In 1998, several parents expressed concern and hesitancy about placing their children in non-kinship day care arrangements. Those who had child care for their children were using kinship care (usually a grandmother and in one case an aunt).

In 1999, parents reported similar types of child care arrangements. One parent was able to keep her job and still get her children from school when they had asthma problems, because when they were not too sick she could leave them with their grandmother for the rest of the day.

Other Child Impact

In 1998, several parents stated that they wished that the lost income could be replaced with assistance in finding the services they needed for their children. In 1999, two parents stated that they thought that the child's school could provide the necessary services, but they were having difficulty getting help. One parent stated that the school did not consider her child's problem to be a medical problem that required their attention. Another parent felt that her child's problems interacting with other children could be helped by a school social worker, but was not satisfied that her child's school's social worker would be helpful for her child, after observing a session with another family. Another child was having significant behavior problems at school, with multiple suspensions having already occurred in the new school year.

8. SUMMARY OF FINDINGS ACROSS CASE STUDY SITES

This section describes the findings from the agency and family interviews, and synthesizes these findings across sites. In presenting this integrated perspective, it is important to emphasize that our findings provide local perceptions and illustrative descriptions of policy impact, as discussed in Section 2. The results of the interviews are not intended to be statistically representative within each case study site, across case study sites, or for the country as a whole. Thus although we present some summary statistics for the family interviews in particular, the resulting percentages should not be interpreted as local or national averages, or as definitive conclusions about the perceptions and experiences of the families or communities overall.

Despite this limitation we believe there are some broader inferences that can be made by comparing findings across case study sites. The experiences reported by families and by agencies are included within the likely range and nature of experiences that occurred following the policy change. The outcomes observed in the case study sites provide insight into how other communities and States may have responded to and been affected by welfare reform, based on different characteristics of their policy environments. The findings also are useful for focusing on possible areas of unmet need and for prioritizing questions for further evaluation. Thus in drawing these broader conclusions, we discuss how family experiences could be affected by differences in the differing policy environments across the states. These findings should help policy-makers and agencies better understand the experiences of affected families and the support systems that they are accessing in the post welfare reform period. Finally, these perceptions and experiences are useful for generating hypotheses that can be tested in the quantitative analyses of this policy evaluation.

Our discussion proceeds by focusing first on the findings from agency interviews and then on the family interviews and the synthesis of agency and family findings. We conclude with a discussion of issues for further study including specific hypotheses arising from the case studies.

8.1 SUMMARY OF FINDINGS FROM AGENCY/PROVIDER INTERVIEWS

This section first describes the reported impact of the policy change on SSA and state disability determination services agencies and then summarizes the effects reported by non-SSA agencies that provide services to children with disabilities. This is followed by a summary of the perspectives from the individuals we interviewed in SSA offices and in other agencies regarding the observed or anticipated impact on former child SSI recipients.

8.1.1 Impact on SSA Regional and Field Offices

SSA's Implementation of the Redetermination Process

Most SSA staff we interviewed in 1998 stated that the initial effort to complete the redetermination of childhood disability cases caused scrambling among staff to meet time targets. Many SSA staff at all levels whom we interviewed in 1998 had reported feeling short-staffed for implementation activities. These activities ranged from development of policies and procedures guiding the redetermination processes to efforts to contact families. While continuing staffing concerns were reported by some of the individuals we interviewed in 1999, the childhood CDRs appeared not to be causing the same volume of challenges that occurred with the redeterminations.

SSA's Implementation of the Re-Reviews (Commissioner's Top-to-Bottom Review)

The re-reviews stimulated a complex process of case review and tracking that was widely reported in 1998 interviews as difficult to implement. Some SSA offices reported that there were not enough resources in the policy division at SSA Headquarters to generate highly refined policies and procedures when the re-reviews were first implemented. Some staff felt that resource constraints caused local delays in interpreting rules and confusion during the initial implementation. In 1999, a number of staff pointed out that many of the earlier challenges in the childhood redetermination caseload arose not from adjudicative complexity but from the complexity of tracking the different subgroups of caseloads. Despite these many challenges, SSA staff also identified some benefits of the re-review process, such as the fact that the re-reviews often enabled the case development procedures to be refined through close monitoring, attention to detail, and an inclusive focus in gathering information about the child. Some staff noted that sometimes the reviews identified the need for more development work on a childhood case where it had been difficult for the staff to know what would be sufficient.

SSA's Implementation of the Dedicated Accounts Policy

The new dedicated accounts policy was distinct from welfare reform SSI eligibility changes but was identified as a significant implementation issue by local SSA offices in 1998 and in 1999. This policy requires that lump sum payments that exceed a specified amount be paid directly to a family's bank account and that recipients be instructed to use these funds for goods and services related to the child's disability. This policy affected those families who received lump sum payments when a cessation was overturned on appeal. A number of SSA staff pointed out the challenges in implementing this provision. Some of the specific challenges included the following: lack of clear guidelines on appropriate uses of the funds; staff time required to monitor the accounts; lack of consequences for family non-compliance; creation of a new role for staff; and potential for parents to perceive an adversarial relationship between themselves and the local SSA office.

Overall Impact of the Childhood Eligibility Changes

Several administrators and staff perceived lasting effects of the childhood SSI changes for SSA staffing and for specific policies and procedures. By 1999, some staff noted important ways in which their roles had changed or had become enhanced. Some of the disability examiners and hearings officers felt that they had gained valuable experience in handling childhood cases. For example, several hearings officers noted that childhood cases in particular require a very detailed understanding of the child's capacities and circumstances. Some of the claims representatives in local SSA offices reported that their roles in interacting with families had become enhanced. Some of these staff felt they were increasingly perceived by families as case managers. They generally attributed the reasons for this perception to the interaction that resulted from the lengthy redetermination process, the new roles stemming from the dedicated accounts policy, and the more frequent interaction between the family and field office staff due to increased work participation and the resulting income reporting requirements for families. Some of the staff we interviewed who took on new responsibilities during the redetermination process hoped that the experience and knowledge they had gained could be applied in the future. Several staff specifically noted that the experiences in interacting with families during the appeals process could be used to inform decisions about the Prototype implementation (see footnote 7).

8.1.2 Impact on Other Agencies and Providers

Handling Medicaid Eligibility for Children

Administrators who were interviewed in the state Medicaid agencies reported that children undergoing SSI eligibility redetermination should be protected from eligibility loss as long as the child met the relevant income criteria. None of the administrators had observed any declining Medicaid enrollment figures that would indicate that children were losing coverage, or knew specifically of any significant coverage losses for the affected children. Not all of the states that confer automatic Medicaid eligibility to SSI recipients had begun implementing disability determinations based on the (now repealed) childhood standard. This was due in part to the volume of childhood cases that continued to be in the appeals process through 1999. The administrators noted that federal and state policies permitted States to allow children to stay in poverty-related Medicaid eligibility groups as long as the same Medicaid benefit was provided. One administrator noted that the data received from SSA on children's SSI status was not always accurate particularly for those children who were under appeal. One state was facing a lawsuit due to the way that Medicaid eligibility redetermination had been handled.

In 1998 as well as in 1999, the administrators we interviewed in the state Medicaid agencies generally felt there were no systematic reasons that a large number of children would lose Medicaid when SSI benefits were lost. However, agency staff in most States (other than Connecticut, where SSI is not linked to Medicaid eligibility) identified possible ways in which a child could lose Medicaid coverage. For example, Medicaid was automatically conferred when the child received SSI. After the loss of SSI, a parent might need to respond to periodic eligibility determinations from the welfare office with respect

to income requirements and for the child's Medicaid eligibility to be maintained. If a family did not respond to these requirements then the child's Medicaid eligibility could be affected.

Continuing Medicaid eligibility for children affected by the age 18 eligibility changes was identified as another significant concern. Several Medicaid agency administrators noted that losses in Medicaid eligibility are possible for these individuals. These individuals are not protected by the BBA "grandfathering" provision, and many state Medicaid programs have only limited eligibility for individuals over age 18.

Maintaining Eligibility for Children in Protective Custody

Administrators interviewed in child welfare agencies reported that they were generally able to keep up with the SSI eligibility redetermination process for children in protective custody, for whom they were the representative payee. Several of the SSA offices described the special efforts they had made to keep records updated for children in foster care and to coordinate with child welfare agencies, to prevent these children from losing their SSI eligibility. Some of the child welfare agency administrators we interviewed in 1998 noted that flexibility by SSA staff in granting good cause for late appeals had been instrumental in ensuring continuity of SSI benefits for children in out-of-home placements. By 1999, several child protective services agencies did note that they had not yet found a way to accept dedicated account funds (as the representative payee) on behalf of a child while in protective custody. Some agency administrators noted that the requirements of dedicated accounts placed restrictions on the funds that the agencies could not accept, or stated that the requirements were burdensome for the agency.

In 1999, the administrators we interviewed stated that they were continuing to monitor the appeals process but that the overall impact on affected SSI recipients in foster care could not yet be determined. Some administrators stated that they were developing ways of identifying children who might be eligible for SSI among the population of children in out-of-home placements. When asked whether more restrictive eligibility criteria might curtail these efforts, the administrators we interviewed generally reported that the SSI changes would not curtail these initiatives.

Impact on Other Public and Private Social Service Providers

Administrators in other public agencies or programs whom we interviewed in 1998 or 1999 typically did not attribute significant changes in their own programs or populations served to the childhood SSI changes. These agencies included schools, Title V Children with Special Health Care Needs programs, and mental health agencies. In 1998, some agencies reported that they had engaged in activities to plan for the SSI changes and to coordinate with other agencies. In both rounds of interviews, the staff we interviewed in these agencies generally reported that the anticipated impact had not materialized. Some of the administrators of Title V Children with Special Health Needs programs felt that children that they served had largely remained SSI eligible. Other administrators stated that the affected families were not always visible due to their varied

needs and the fact that the affected children are not necessarily part of any organized system or public program such as Title V, mental health, or child welfare. Some administrators in mental health agencies and in child welfare agencies noted that children currently in their caseloads had appeared not to be affected but that children at risk for needing their services might be affected. Most but not all administrators of these programs noted that they had not traditionally tracked children receiving SSI as a specific subgroup within the population they served.

Several agency administrators noted that the overall welfare reform changes had such significant impact on the populations they served that it was difficult to discern the specific impact of SSI changes from the overall policy impact. Some administrators and legal assistance program staff stated that the circumstances of the affected children and their families may not become evident to child support programs until those families whose circumstances deteriorate reach a crisis stage.

8.1.3 Observations on Family Response and Impact

Beneficiary Appeals and Requests for Benefit Continuation

In 1998, most SSA staff we interviewed who had contact with families felt that many parents who did not appeal initially had understood the eligibility change and believed that their child no longer qualified for SSI. Some SSA staff had some concerns that continued efforts on the “failure to cooperate” cases could create a public relations problem for the agency. Several staff members stated that some parents felt that they had made the correct decision not to appeal and that continued efforts by SSA staff to explain their options for appeal and in some cases to contact a third party to explain the family's option to appeal were not always welcomed. By 1999, several staff members continued to report that among those families who explained why they were not pursuing further appeals, most stated that they understood the eligibility changes and why their child did not qualify for SSI under the new eligibility criteria.

In general, those staff we interviewed in 1999 who knew of parents who were re-applying for a child with ceased benefits felt that the parent was usually responding to a child's worsening health status. Some of the staff who interacted with parents filing new applications for a former childhood SSI recipient observed that the parent was citing a different type of functional impairment. Most field office staff did not yet know what impact parents' decisions to accept benefit continuation during appeal might have for the children whose SSI cessations were ultimately upheld. The outcomes of final appeals were just beginning to be known at the time of the final interviews.

Observations on Beneficiary Responses

Some SSA staff reported in 1998 that families were reporting more interest than they had in the past in how to get and maintain jobs. Many families were thought to be turning to public assistance at least as a temporary step to replace the lost SSI income. Most SSA field office staff we interviewed in 1999 had observed significant changes in the

volume of income reports. Families were reporting additional sources of income, and SSA also was receiving a larger volume of wage alerts about work that families might not have yet reported. The staff also noted that some parents had changed jobs once or multiple times over the past year. Several field office staff observed that some of the parents might have more difficulty finding or retaining work under more adverse economic circumstances.

Observations on Beneficiary Impact

Most agency administrators and staff we interviewed in 1998 felt that because many families were using the SSI income for overall needs rather than specifically for the child's disability, they did not expect any immediate specific effects of the income loss on the child's access to health or mental health services. Several legal advocates and child welfare administrators we interviewed in 1999 noted that the impact of income loss—either SSI alone, or in combination with other public assistance losses—could take time to manifest. A number of these individuals expressed concern about the possibility of deterioration within the family over time and about this deterioration of conditions leading to future crisis.

In general, the administrators and staff we interviewed in 1998 and 1999 expressed general concerns about the well-being of the affected children due to limitations of the service system and due to the difficulties that many low-income parents can have in finding services, and in advocating for the child's needs. These concerns focused on the availability of services for the population of children affected by the new SSI childhood eligibility criteria. Retention of Medicaid eligibility was noted as important by a number of administrators. The administrators we interviewed were more frequently concerned about the combination of income loss and its associated stress within the family with the service system gaps that were present in the local community. Specific examples that were provided by these administrators included the availability of mental health services for children, and the availability of family support services for children who were not yet in a crisis situation. Some administrators observed that there was more pressure on families to search for the services needed by the child and to ensure that the child remained enrolled in Medicaid, for example.

Agency administrators focused on future sources of income for children reaching age 18 as a particular challenge. Access to Medicaid coverage or to other health insurance options also was mentioned as a concern for the children reaching age 18. Several administrators noted that these individuals are not always part of a program or system that can provide the necessary support or advocacy for them. This population was identified as having unique needs but also being difficult to track with respect to policy impact.

Observations on Medicaid Enrollment

A number of agency administrators and providers we interviewed stated that they had anticipated more Medicaid eligibility problems for affected children than were

generally observed or heard about so far in the redetermination process. In 1999 as well as in 1998, some perceived that those Medicaid problems that had occurred were sporadic rather than systematic. Some administrators speculated that the decline in attention to the issue made those families who were experiencing problems less visible. A number of administrators and providers reported the concern that some children's Medicaid eligibility would lapse not because of a state's eligibility restrictions but because of the responsibility placed on families to retain or restore the coverage. For example, a number of agency administrators raised concerns about whether families would follow through with the local social services office when Medicaid eligibility was lost due to SSI eligibility changes. These concerns focused on those children who were not eligible through the Medicaid grandfathering provision but who still might meet eligibility criteria for another public health insurance program.

In most states, in 1998 it was not yet clear how the grandfathering provision would be handled by Medicaid and disability determination agencies. By 1999, the fact that the appeals process was continuing for many families meant that the grandfathering provision had not yet been tested and thus could not be evaluated. Overall, most Medicaid agency administrators we interviewed felt that loss of Medicaid eligibility would not be a major issue for children under 18 years of age. This was attributed to broadening eligibility and to temporary policies that the agencies had put in place to maintain Medicaid eligibility for children affected by the SSI policy change.

8.2 SUMMARY OF FINDINGS FROM FAMILY INTERVIEWS

This section describes findings from our interviews with parents regarding their reported experiences with the eligibility redetermination process, their responses to the potential loss of SSI income, and their perceptions of the impact on the child and their family. In addition, we discuss whether there are noticeable patterns in family outcomes associated with differences in the state-level policy environment. We describe family experiences and changes through the end of the study period in 1999 along with some of the changes that occurred early and later in the study period.

One objective of the study was to identify possible differences in response and impact across the sites. The small number of participating families in each site means that the percentages associated with a site can change significantly based on one family's response. In tables describing characteristics of participating families and the findings from family interviews, the minimum and maximum values by site are provided to characterize some of the variation across sites without using potentially misleading percentage values. Percentages are provided for the totals that combine the sites, however.

Table 8.1 summarizes selected characteristics of the families interviewed in 1998. These characteristics include family composition, use of public assistance and SSI within the family, and work participation prior to the SSI eligibility changes. The last two columns show the total responses combining all five sites and the percentage distributions for the totals.

Table 8.1
Summary of Family Characteristics and Range Across Sites in 1998

	Range across sites		All sites combined Total	
	Minimum	Maximum	No.	%
Total interviews			44	
Family Composition				
Single parent family	5	10	32	73%
Two parent family	0	4	6	14%
Grandparent/kinship foster care	0	2	6	14%
Use of Public Income Assistance				
Families with > 1 child SSI recipient	0	3	8	18%
Families receiving any non-SSI income assistance prior to SSI change	3	5	22	50%
Families receiving SSI for other family member but no other income assistance prior to SSI change	1	2	6	14%
Family Work Participation				
Parent(s) working prior to SSI change	3	7	20	45%

Table 8.2 provides a summary of the findings with respect to key evaluation questions. Specifically, Table 8.2 summarizes the redetermination experiences and outcomes of families, the characteristics of families, and the responses of families to the eligibility changes as reported in 1998 and as of the end of the study period in 1999. Percentages for responses about eligibility redetermination and the child's current SSI status use a denominator of total respondents in the interview year (i.e., 44 families in 1998, and 35 families in 1999).

All percentages for the responses in the family impact categories use a denominator of the 44 families who participated in the 1998 interviews. Nine families could not be interviewed in 1999 because they could not be contacted or because an interview could not be scheduled. Certain outcomes that these families reported as of 1998 are included in the summary findings for 1999 as well as for 1998 where appropriate (e.g., total families who ever reported loss of Medicaid eligibility for the child). Using 1998 data for other outcomes for these families may not reflect their actual status in 1999. Because several families who were interviewed in 1998 and 1999 reported fluctuations in income and public assistance, for example, it is possible that changes also occurred in these outcomes

for some of the families lost to follow-up. Generally the overall results were not affected by the inclusion or exclusion of 1998 outcomes for these families. Those outcomes that are sensitive to the inclusion of 1998 findings (e.g., Medicaid loss without restoration) are identified as such in the text with the impact of loss to follow-up specified.

8.2.1 Experiences with the Eligibility Change and Redetermination

Experiences with the Redetermination Process

In 1998, most families stated that they understood the initial letters from SSA that explained the welfare reform changes, the eligibility redeterminations that were beginning, and the option to appeal any cessation of benefits. Many families expressed initial confusion about how the appeals process worked. In a few instances, some of the difficulty was attributed to language barriers although in other families non-English speaking parents stated that they had ready access to translators and translated materials. Most of the families who were non-English speaking reported that they were able to understand materials and that not having English proficiency did not adversely affect their understanding of the redetermination process. In 1998 and 1999, a number of families who had gone through a hearing for their child stated that the hearing officer had helped them to better understand the process and what was being considered in the redetermination.

The 1999 interviews also focused on the parent's decisions about initial as well as subsequent appeal options. Several families reported in 1999 that they had missed scheduled appeal hearings over the past year. The reasons given ranged from hospitalization of the parent or a family member at the time that the hearing was scheduled to confusion within the family about which parent was going to attend the hearing. Several parents reported that they had ignored one or more letters from SSA about a step in the redetermination process but had continued with the process after receiving encouragement from another family member or friend.

Table 8.2
Summary of Family Impact and Range of Responses Across Sites

	1998			1999		
	Range Across Sites	Totals		Range Across Sites	Totals	
	Min, Max	No.	%	Min, Max	No.	%
Total interviews		44			35	
Not available for follow-up interview		N.A.			9	
Current SSI status						
Eligible	0, 1	1	2%	0, 2	7	20%
On appeal	4, 7	29	66%	0, 2	5	14%
Eligibility ceased	2, 4	14	32%	3, 6	23	66%
Redetermination Experiences ^{a, b}						
Appealed	4, 8	29	66%	4, 9	30	68%
Requested benefit continuation	1, 5	15	34%	1, 5	17	48%
Paying back overpayment	0, 1	1	2%	0, 1	2	5%
Received dedicated account	0, 1	1	2%	0, 1	3	7%
Sought/seeking legal assistance	0, 1	2	5%	0, 2	6	14%
Was declined legal assistance	0, 1	1	2%	0, 1	1	2%
Medicaid and Health Care Access ^{a, b}						
Ever lost Medicaid	2, 3	11	25%	2, 4	12	27%
Ever lost Medicaid and not restored	1, 2	6	14%	1, 2	6	14%
Switched/anticipate switch to prepaid health plan (PHP)	0, 2	5	11%	0, 3	5	11%
Medicaid/SSI loss impaired access to health care	1, 3	11	25%	1, 4	8	18%
Switched to private health insurance	0, 1	1	2%	0, 3	6	14%
Socioeconomic Impact ^{a, b}						
Increase in family income	0, 3	6	14%	1, 3	11	25%
Decline in family income	4, 8	28	64%	4, 7	28	64%
Increase in use of (non-SSI) public assistance	2, 3	11	25%	0, 2	5	11%
Decline in use of (non-SSI) public assistance	0, 3	8	18%	0, 3	5	11%
Parent(s) eligible for workforce (non-disabled/non-elderly)	6, 8	35	80%	6, 8	35	80%
Parent(s) currently working	5, 8	29	66%	5, 7	30	68%
Parent(s) increased working hours or took new job	1, 4	13	30%	3, 5	20	45%
Has applied for child support	0, 3	8	18%	1, 3	10	23%

Table 8.2, Continued
Summary of Family Impact and Range of Responses Across Sites

	1998			1999		
	Range Across Sites	Totals		Range Across Sites	Totals	
	Min, Max	No.	%	Min, Max	No.	%
Living Arrangements ^a						
Family has moved	0, 4	11	25%	1, 4	12	27%
Change in custody/caregiver	0, 1	2	4%	0, 2	5	11%
Other household composition change	0, 3	5	11%	0, 4	9	20%

^a Round 1 (1998) information is used for the 9 families lost to follow-up in Round 2 (1999). Thus the denominators for 1999 percentages are based on the total of 44 families who participated in 1998

^a For both 1998 and 1999 interviews, the changes are relative to the time period prior to notification of SSI eligibilityredetermination.

In 1998 we interviewed a number of families who had not initially appealed the child's SSI cessation but did appeal after receiving the "good news" offer of late appeal in early 1998. In 1999, a small number of these families who appealed after the "good news" letter and received benefit continuation during this appeal stated that the initial cessation had been affirmed and that they were now faced with benefit overpayments. This had happened very recently for most of the parents who reported this outcome. While each of the parents felt they knew from the beginning that they might have to repay the benefits received during appeal, they were concerned about being able to repay the funds. Most but not all of the families stated that they knew they could request a waiver of repayment. Of those families who had been notified of an overpayment due to benefits received during appeal, only one had requested a waiver and also received a response by the 1999 interview. This family reported that the request for a waiver of overpayment had been denied but was not able to report the specific reason.

Family Use of Legal Assistance

Two families reported in 1998 that they had sought legal assistance. By 1999, a slightly larger number of families (6) had sought legal assistance at some point in the redetermination process. The number of families who sought legal assistance comprises approximately one-fifth of those who filed an appeal. Of those families who explained why they had not sought legal assistance, most stated that they felt that involving a lawyer would create its own problems, or that they were not sure whom to contact. These families generally recalled receiving information from the SSA field office. Several families stated that they had not been denied help when they contacted an attorney or legal assistance agency but said they were told to call back in a later stage of the appeals process. This was consistent with what some legal advocates stated in the 1998 or 1999 interviews. These advocates explained that attorneys sometimes had encouraged families

to obtain legal assistance only after a cessation occurs. One family had sought but had been denied legal assistance due to what the family believed was the attorney's assessment of the strength of the case. Several additional families reported that they had initiated contact with a legal assistance agency but had not followed through or had not received a phone call in return. The single interviewed family that had exhausted all levels of appeal and denied an overpayment waiver reported having just obtained legal assistance.

Outcome of the Redetermination Process

In 1998, about two-thirds of the families interviewed reported that they had appealed an initial cessation decision, and about half of those that appealed stated that they had requested benefit continuation. In 1999, an additional family reported that they had appealed since the last interview. By 1999, about one-fifth of the families who were re-interviewed stated that the child had been found to be eligible for SSI and was receiving benefits. Another one-fifth of the families believed that the child's SSI eligibility was still in the appeals process. In the remaining majority of families, the child's SSI had been ceased and no appeal was pending.

Parents were asked in the 1999 interviews whether they had re-applied or were considering re-applying for SSI for the child. In a few cases in 1999, the parent had re-applied for benefits for the child or was planning to re-apply. One parent stated that she had filed a new application for the child rather than an appeal due to a paperwork mix-up with the appeal that she believed she had filed earlier. Another parent felt that she would very likely file a new application for SSI for the child. The parent explained that while the child had been doing well since the loss of SSI, the child's health problem had recently worsened. As in 1998, most parents whose children's SSI had been ceased with no appeal pending stated that they felt the child no longer met SSI eligibility criteria.

Three families who had not requested benefit continuation had received dedicated accounts during the study period. The single family that had received a dedicated account for the child in 1998 had reported problems stemming from spending the funds without authorization from the local field office. The two families that received these accounts between 1998 and 1999 had not encountered any difficulties although only one of these two families had used any funds by the time of the interview. One of the three parents described the purpose of the funds as relating to the child's specific disability while the other parents described the purpose as for the child generally.

In 1999, those parents who received benefit continuation during appeal were asked about the child's current appeal status and possible overpayment requirements if a cessation was upheld. About one-third of the families who appealed and requested benefit continuation said that they had been notified of an overpayment requirement because the child's earlier benefit cessation had been upheld after appeal. Several families had sought or planned to seek waivers of the overpayments. Two of the 17 families who requested benefits during appeal were making monthly payments.

8.2.2 Impact on Medicaid and Health Care Access

Medicaid Eligibility and Enrollment

Loss of Medicaid occurred in each of the sites. In 1998, about 25 percent of parents reported that their child had not retained Medicaid coverage after losing SSI. As indicated in Table 8.2, a total of six children (14 percent) had lost Medicaid and had not had it restored by 1998. There was little change in Medicaid status between 1998 and 1999. By 1999, about one-fourth of the families reported that the child had lost Medicaid eligibility for some period of time following the SSI eligibility changes. Given complex and varying Medicaid income and resource limits by site and the study's methodology, it was not possible to determine whether any of the children not currently enrolled were actually eligible for Medicaid.

There were no clear patterns of Medicaid retention across the five sites for children under 18 years. All of the children who lost Medicaid eligibility and had eligibility restored were eligible by the time of the first interview in 1998 and had retained coverage through 1999. We did find that in the one site within a state that does not link Medicaid with SSI eligibility (Connecticut), the only child who lost Medicaid and did not have it restored had reached age 18. Results from family interviews suggested that Medicaid coverage past age 18 was a more frequent problem. Approximately half of the children who had lost Medicaid and not had it restored (to our knowledge) by 1999 had reached 18 years of age. Two of the three children who lost Medicaid by 1998 and were reported to still be without Medicaid coverage in 1999 had reached age 18. Three of the six children who had lost Medicaid and had not had it restored by 1998 were lost to follow-up in 1999. This included one child who had reached age 18 in 1998.

Most children under 18 who had not retained continuous Medicaid coverage since welfare reform had either re-enrolled in Medicaid or had been enrolled in private health insurance. Only one child was known to have lost Medicaid and to be without any health insurance by 1999. This child had reached age 18 by 1999. This individual lived with a parent on SSI and thus did not have access to employer-based private health insurance through the parent.

Several parents were not absolutely sure whether the child was still covered by Medicaid or whether coverage had been terminated. These parents explained that they were not sure because they had not tried to use the child's Medicaid benefit identification card recently. It is important to note that the family income information gathered in the interviews was not adequate for determining the child's current Medicaid eligibility. Other than the reason reported by the family, it is not possible to know why a child was not enrolled in Medicaid. It is possible that some children were eligible but not enrolled. Some may no longer meet Medicaid income or resource requirements.

Transitions to Prepaid Health Plans

In 1998, several parents stated that their child had been enrolled in a managed care plan since losing SSI. Several other families reported in 1998 that they expected the child

would have to change from fee-for-service to a Medicaid managed care plan. Families affected by such switches ranged from none in two sites to two families in another two sites. In 1998, several parents voiced concerns about having to enroll the child in a PHP. By 1999 none of the families who were re-interviewed voiced concerns about future transitions to Medicaid PHPs.

Some families reported specific problems that they had encountered for their child in a managed care setting. Finding a physician that the parent trusted to care for the child's specific health problem was raised by families in several sites. For example, one parent felt that under fee-for-service Medicaid, it was possible to find a mental health provider by calling from a list of Medicaid providers. Since the child had enrolled in a managed care plan, however, the parent had been unable to find a mental health provider who would see the child. Other families who enrolled their child in commercial health insurance after losing Medicaid had experienced benefit restrictions or lack of provider choice that were barriers to the care needed by the child. Several parents reported that the child was going without over-the-counter or prescribed medications for financial reasons

Use of Private Health Insurance/SCHIP

Across the five sites, only one family reported in 1998 that they had restored health insurance coverage for the child by taking a new job that provided health insurance benefits. By 1999, this family had re-enrolled the child in Medicaid due to the out-of-pocket and premium costs of private employer-based health insurance. By 1999, another parent had obtained private health insurance for her child (who was over 18) through her employment.

Another parent was court-ordered in 1999 to provide private employer-based health insurance benefits for her child now in foster care. This parent received a reprieve shortly after the court order was implemented and dropped the private employer-based insurance. This was one of two parents who specifically identified SCHIP as an insurance option and the only parent who had applied for SCHIP. When the application was filed, the parent was told that the child was income eligible for Medicaid and thus did not qualify for the state-only SCHIP plan.

Several families already were using private benefits for their child with Medicaid as the secondary payer prior to welfare reform. A very small number of families across the sites said that they knew of their state's SCHIP program as a possible insurance option if Medicaid eligibility was lost. None of the families reported having enrolled the child or other children in the family in the SCHIP program. In those States in which SCHIP is a Medicaid program expansion, it was not possible to determine whether a child re-enrolled in Medicaid was enrolled in SCHIP (i.e., the expansion of Medicaid income eligibility due to SCHIP) or in a Medicaid eligibility category that had existed prior to welfare reform or in the "grandfathered" eligibility group

Access to Medical and Mental Health Services

In 1998, parents in approximately one-fourth of the interviewed families stated that the child's loss of Medicaid and/or SSI benefits had impaired the child's access to medical and/or to mental health services. The number of families who felt that the loss of SSI income either directly (or indirectly through effects on Medicaid coverage) affected access to services ranged from one to three of the families in each of the sites.

A larger number of the parents interviewed reported that they were having difficulty finding the necessary services for their children. In most cases, the parents did not attribute these problems specifically to the loss of SSI. The most frequently reported difficulty in 1998 was lack of knowledge in how to go about finding an appropriate provider for the child's mental health needs. In both 1998 and 1999, the access difficulties raised most often by parents were not related to the child's loss of Medicaid or to fear that the child would lose Medicaid. The problems that were raised included the following: (1) finding a psychiatrist or appropriate pediatric specialist who participated in the Medicaid program; (2) finding preventive or rehabilitative child welfare services to address problems within the family and (3) getting the appropriate medications for a child given restrictions in the Medicaid formulary. Several parents felt that their children were not receiving the care that they needed for a psychiatric problem because the parent had not found a provider who participated in Medicaid and who also met the parent's requirements (e.g., experience in pediatrics, training in psychiatry rather than in family practice). Parents emphasized quality as an important concern. Several parents who had a continuous relationship with a child's provider noted its value to them. One parent felt that having SSI in addition to work income might have been a disadvantage to the family when seeking child welfare services for the child. This parent reported having been told by service agencies that the child did not meet income eligibility criteria and was only able to access mental health services once the child was placed in out-of-home foster care.

8.2.3 Socioeconomic Impact

Economic Impact

In 1999, most families whose child's SSI benefits were ceased reported that their household income was lower than it had been prior to welfare reform. Some families had temporarily increased total income by requesting SSI benefit continuation during appeal at the same time that they sought other public assistance. Many families said they had turned to public assistance following the loss of SSI income. Of these families, most turned to welfare and Food Stamps programs to compensate partially for the income loss. For some families, the increased use of non-SSI public income assistance appeared to be a short-term response. The number of families who stated that their current use of non-SSI public income assistance was higher than it had been prior to the loss of SSI was eleven (11) in 1998 and five (5) in 1999.

By 1999, reported household income had declined in about two-thirds of the households. Income was the same in a very small number of families and had increased for the other one-fourth of households. The most frequent reason for increased household

income was an increase in earned income. A smaller number of families had higher household income due to an increase in unearned income from TANF, Food Stamps, or SSI for another family member.

Response to the Potential Income Loss

Most families that already were receiving an AFDC/TANF cash grant when the SSI changes occurred stated that they had added the child to the existing cash grant. By 1999, about one-fifth of the families had increased their use of public income assistance (other than SSI), and several additional families had started receiving public assistance. Due to increased work participation and to approaching time limits, about the same proportion of families (one-fifth) stated that they had reduced their use of public assistance by 1999.

A few families were approaching their time limits for cash assistance in 1998, but had not yet been affected by this income loss. Several families had turned to Food Stamps or emergency assistance. By 1999, parents in all of the families that had reached public assistance time limits had been able to find work.

Several parents stated that in response to welfare reform, they filed new applications for child support from absent fathers. Several other parents were already receiving child support or had filed applications prior to welfare reform but had not yet received benefits. Most families who filed new applications had done so by the 1998 interview. One family started to receive child support for the first time between the 1998 and 1999 interviews.

Work Participation

Particularly in states such as Connecticut and Michigan that were further along in implementing features of national welfare reform such as time limits for public assistance, parents were returning to or newly entering the work force in 1998. By 1999, all but one of the parents interviewed in each site (excluding elderly guardians and parents with disabilities) was working. Several of the parents who were not working prior to welfare reform were in school at the time and stated that they had planned to enter the workforce even before the SSI changes occurred. The percent of parents in the workforce did not change between 1998 and 1999. These rates were 66 percent and 68 percent of parents, respectively. Among the parents who were not disabled or elderly, 83 percent in 1998 and 86 percent in 1999 reported that they were working.

About half of all families reported that they had newly entered the workforce or increased their working hours due to welfare reform. None of the parents who started working only after welfare reform reported that they had had difficulty finding a job. By the 1999 interviews, several parents were just completing training programs and had not yet been hired.

Several families reported in 1998 that they had recently quit jobs or reduced working hours due to the demands placed on their time by their children. Several parents reported that they were unable to work or were having difficulty working while also

meeting the child's needs because they had to be available when problems occurred at school. By 1999, none of the families reported having lost jobs for this or any other reason although some had changed their jobs. Some families stated that they had been able to establish child care arrangements with relatives when behavior problems or physical problems interrupted the child's school day. Other families explained that the child's problems had improved over time and was not interfering with the parent's work. Several parents whose children had significant behavior problems remained out of the workforce.

8.2.4 Caregiving and Other Child Impact

Living Arrangements

As described in the methodology, we interviewed several foster parents who were *payees* for a child SSI beneficiary, but we excluded from our sample any children who were in foster out-of-home placements and had an *agency payee*.

All caretakers of children in foster care whom we interviewed were relatives of the child(ren). In 1998, two of the six foster caretakers (all six of whom were grandparents or great-grandparents of the child) expressed concern that they would not be able to continue caring for the children due to the income stress. By 1999, one of these foster grandparents had given up custody of the child to another relative due to the loss of SSI. The other grandparent was considering giving up custody for the following specific reasons: loss of SSI; low foster care payment received for the child (as a kin caretaker); and inability of the grandparent to work because of the child's behavior problems at school.

About one-fourth of the families had moved since losing SSI income. Several of these families attributed the move to income loss. Several had moved for other reasons. In 1998, one family reported having a period of homelessness after losing the child's SSI income. This family was able to stay with several different relatives and subsequently found another housing situation. Few additional moves were reported in the 1999 interviews. Several additional families experienced changes in household composition between 1998 and 1999 due to marriage or due to separation of the parents.

Child Care

In 1998, nearly all parents with young children reported that they relied on a family member or personal friend to provide childcare rather than a child care/daycare center. Parents who had young children and were newly entering the work force generally reported that they were receiving childcare subsidies through public assistance programs. By 1999, none of the parents reported having difficulties finding child care. All of the children who lost SSI in the families we interviewed had reached school-age by the date of the first interview. Thus after school care and school absences were the common issues raised by parents.

Parents commonly reported a problem with being available to bring their child home from school for behavior problems (or for physical health problems in one case). This problem was preventing one grandparent who had been in the workforce prior to taking custody from rejoining the workforce. Another parent who experienced this problem stated that because there were other jobs available, she had been able to change to a work situation that allowed her some flexibility in leaving for the child's school. Several other parents were newly entering the workforce in 1999 and anticipated that school absence imposed by the child's problem could interfere with their working but had not yet experienced this problem.

Other Child Impact

By 1999, few of the parents attributed changes in their child's health status to the change in SSI eligibility. Nearly all parents stated that their child's overall health, functional status, and school performance had remained the same or had improved. Those parents who reported that the child was not improving or had declining function pointed to the inaccessibility of services for the child—medical care, mental health services, and/or family support—as the most significant contributing factor. For the most part, the parents we interviewed did not attribute the child's problems to the loss of SSI. Several parents attributed the problem to the loss of Medicaid imposed by the SSI loss. Other parents attributed the problem to their increased work participation required by the SSI loss or by TANF changes that subsequently resulted in Medicaid loss due to higher household income.

In the 1998 and 1999 interviews, it appeared that parents who were able to establish an ongoing relationship with a specific provider, or whose children had secured the interest and assistance of a particular teacher or school staff member, had been able to assemble a set of resources for the child that were improving the child's function and future prospects. For example, several such parents reported that their child's provider called periodically to check up on the child and family even after Medicaid coverage was lost or the parent could not continue paying out-of-pocket for continued visits. Many of the interviews with agency administrators confirmed that the population of affected children had varied service needs and had different levels of involvement with a variety of different service systems.

In the single rural site visited, several parents expressed concern about their teenage child's job prospects due to specific physical disabilities. The parents had observed the child's difficulties with undertaking agricultural work and did not know of other local work opportunities for the child.

8.2.5 Impact of State Policies on Child and Family Outcomes

Medicaid Eligibility and Enrollment

There was not a clear relationship between Medicaid eligibility policies and continued Medicaid enrollment for children across the sites. Medicaid eligibility was lost

at least episodically for at least one child under age 18 years in each site. The interviews with administrators and with families are consistent with several explanations for Medicaid loss. Medicaid and other children's agency administrators we interviewed pointed to the complexity of Medicaid rules and to difficulties in having timely data on appeals status as challenges to Medicaid retention.

The 1999 interviews identified some of the more lasting effects on Medicaid enrollment once states were past the initial implementation of the policy changes and after families moved further into (and past) the appeals process. However, the complexity of Medicaid eligibility within and across States makes it difficult to determine whether any of the children in the interviewed families who were protected by the 1997 BBA grandfathering provision actually met the necessary eligibility criteria during their episodes of Medicaid loss. The second round of case studies took place before some of the children could be affected by Medicaid provisions regarding disability determinations for the "grandfathered" cohort of children.

The appeals process continued for some families we interviewed as well as for the national cohort of affected children through the period covered by the 1998 and 1999 interviews. Our findings from interviews identified Medicaid enrollment issues that were related to potential confusion by caseworkers or families or that resulted from information system discrepancies with respect to the child's SSI appeal status. In all States visited that confer Medicaid automatically to SSI recipients, the SSI loss was reported as placing some responsibility on the parent to demonstrate income eligibility to the welfare agency. Of several parents who reported being sent between SSA and their welfare office caseworker to sort out Medicaid problems, some parents continued to pursue the child's eligibility while a small number did not. Overall the findings from agency and family interviews underscore the sensitivity of children's retention of Medicaid to family compliance with reporting requirements and to family persistence when problems arose in the child's eligibility status at the welfare office or when the child visited the provider.

One family whose child entered an out-of-home placement prior to the 1998 interview but after losing SSI stated in 1999 that the dependency court had ordered the parent to provide private health insurance to the child. This parent was not sure whether the child continued to be enrolled in Medicaid but had explained to the child that the family did not have the financial resources for the deductibles and copayments that applied to the private insurance. Because our sampling methodology largely excluded children who were in foster care or who entered foster care after 1996, we were not able to explore whether this was a rare occurrence.

In general, administrators of child support programs raised concerns about Medicaid for the children reaching age 18. Results from family interviews identified a higher rate of Medicaid loss without restoration for this group of affected children. A general theme from the family interviews was the importance of family circumstances for this outcome. For example, an 18 year old in one family retained health coverage through the commercial insurance option from the parent's new job. In contrast, an 18 year old in another family received no health insurance benefits through the 18 year old's new job.

Moreover, because his parent received SSI, obtaining health insurance through the parent was not an option.

Transitions to Medicaid Managed Care

California was the only one of the four case study states in which the loss of SSI-linked Medicaid could expose the child to a mandated managed care participation requirement. Several agencies identified such participation changes as a likely outcome, and this was supported by findings from the 1998 family interviews. No additional transitions were reported in the 1999 interviews. In California, Medicaid eligibility linked to SSI does not confer mandatory participation in managed care in the two counties we visited. Some but not all families who enrolled their children in Medicaid managed care in these counties after losing SSI believed that managed care was a requirement. None of these families reported specific advantages or disadvantages of such participation, however.

The only specific problem relating to Medicaid managed care that was voiced by families we interviewed was finding a mental health provider for the child. One example occurred in a California county where most mental health services are not included within the managed care plans. The specific problem reported by one family was finding a mental health provider within the managed care participating provider list. The parent felt it was necessary to obtain a referral from the child's provider in the managed care plan to access care that in the past could be accessed directly. While managed care participation could contribute to care coordination, in this instance the parent perceived the plan as a barrier.

States' Title XXI (SCHIP) Child Health Insurance Expansions

Agency administrators in the case study sites often raised the new SCHIP program as an alternative to Medicaid. Few parents mentioned the SCHIP program as an option for their child or for other uninsured children in the household. None reported that they had enrolled any of their children in SCHIP. It is important to note that families were asked about any health insurance alternative to Medicaid. It was not expected that families would be able to differentiate between Medicaid and SCHIP-related income eligibility expansions to the state's Medicaid program. Those who lost and then regained Medicaid coverage may have become eligible within a Medicaid eligibility category that resulted from the SCHIP eligibility expansion. By 1999, relatively few children had lost Medicaid for an extended period. Moreover, most of those affected had reached age 18 and thus were not the target population for SCHIP health insurance expansions. Thus it is not surprising that SCHIP expansion characteristics of the states (e.g., enrollment of the eligible population, scope of expansion) did not appear to be associated with patterns of Medicaid loss and of health insurance status reported by families.

States' Welfare Reform Provisions

In the states with 24 month time limits for consecutive months receiving TANF benefits and with earlier TANF effective dates, it was expected that families might respond

more quickly to SSI loss in terms of work participation. This tended to be supported by the family interview findings in 1998. Families in Connecticut and Michigan were either entering the workforce or stated that they were expecting to have to enter the workforce and also described the issue of impending time limits in the interviews. Families in the California sites where time limits had not yet taken effect by 1998 tended not to raise the specific details of TANF restrictions. By 1999, families in all of the sites—with the exception of Los Angeles—reported being affected by time limits or work requirements, or stated that they had dropped public assistance because of knowledge of time limits. Several stated that the total work hours requirement might pose a problem in the future. None of the families we interviewed had sought exemptions from TANF time limits or from work participation requirements. Thus it was not possible to link reported family experiences with work requirements or exemptions with the specific elements of the state's TANF program.

8.3 ISSUES FOR FUTURE STUDY

The purpose of the first round of interviews was to explore the initial impact of the policy change on children and their families and to understand how SSA offices and other agencies responded. The first round identified family experiences with the redetermination process and provided illustrative descriptions of local implementation issues and impact. The second round of interviews focused on the consequences of the redetermination process for families, on their responses to the SSI loss, and on their expectations for future impact for the child and family. These findings demonstrate how some of the initial concerns raised by parents and their expectations of impact were realized. The duration of the post-cessation appeal period means that some families we interviewed had not yet completed the redetermination process by the 1999 interview. Coupled with the small number of study participants, the delay in policy implementation underscores the need for continued evaluation of policy impact. Finally, the complexity of local service systems for children with special health needs means that both the scope of agencies and programs, and the range of possible effects, should be broadened to capture policy effects over time. Overall, the perceptions and experiences reported in both rounds of interviews produced a range of questions for further study in the quantitative analyses, as well as outside the confines of this study. A set of questions for the quantitative analyses are presented in Table 8.3.

A number of key questions focus on what happens to parent participation in the workforce and family income. For example, there is some question as to whether families will be able to maintain newly acquired work positions due to demands of their child's needs. Families may also be affected by changes in the economic environment, for example, if labor market prospects improve or deteriorate in the future.

The longer run consequences for health insurance coverage and family income also have implications for the longer run health and well-being of affected children. In the second round of interviews, there was an opportunity to determine if there are subsequent changes in children's access to needed medical care, in the child's health or functional status, and in other areas of functioning such as school or employment, for the responding

families. However, several families were still in the appeals process. Moreover, an additional group of parents who requested benefit continuation during appeal and whose child's SSI cessation had been affirmed on appeal, had just received overpayment notification at the time of the 1999 interview. Whether or not these parents receive waivers, make payments, or do not respond to the overpayment requirements may have potential short term implications, or long-term implications on future income.

In terms of agency activities, the case studies identified a set of emerging activities around the identification of children with potential SSI eligibility. Both States and localities reported efforts underway to improve the identification of children potentially eligible for SSI within foster care and/or other populations of children, through the use of screening tools. Moreover, as the policy implementation continues along with states' broader welfare reform and Title XXI (SCHIP) changes, it would be informative to observe how other state policy factors affect responses to and the effects of the policy change. Examples of such policy factors include Medicaid eligibility policies streamlined eligibility through coordinated public income and public health insurance eligibility assessments, or innovations in child welfare related delivery systems

Table 8.3
Summary of Questions for Further Study

Questions for Further Study
<u>Medicaid and health insurance</u>
<ul style="list-style-type: none">❑ What proportion of parents reapply for SSI for a child whose SSI was ceased, what are the primary reasons for reapplication and how many children are found eligible?❑ What proportion of children lose Medicaid and do not have it restored due to income eligibility, and due to the child not meeting the BBA grandfathering provision?❑ What proportion of children maintain Medicaid coverage but are moved to an eligibility category that alters their managed care participation or benefit options once the appeals process is completed?❑ What is the relationship between a state's transitional Medicaid policies and patterns of parents invoking this coverage when working hours and/or salary increases take place?❑ What proportion of affected children who are not Medicaid eligible participate in SCHIP?❑ Do children who receive private health insurance through a parent's employment sustain this coverage over time?❑ What is the retention of Medicaid for children whose eligibility is determined at age 18, and for children with cessations who reach age 18?❑ Do children who reach age 18 and maintain Medicaid eligibility continue to be enrolled?❑ Do children reaching age 18 have options for and affordable coverage through a parent's employment, or through their own employment?❑ What health insurance options exist for and are used by children reaching age 18 whose parents are not in the labor force due to disability of the parent?
<u>Access to health care</u>
<ul style="list-style-type: none">❑ Does access to health services improve or decline with loss of Medicaid or of SSI income?❑ Does cost-sharing apply under private insurance or under alternative Medicaid options, and what is the impact on utilization?❑ How does the availability of health services in the community interact with the loss of SSI income in contributing to impact on health care access?
<u>Income</u>
<ul style="list-style-type: none">❑ For what reasons do parents maintain or not maintain their employment status over time?❑ How has parent willingness or ability to work influenced children's access to health care coverage and services?❑ For what reasons do parents with overpayments receive waivers, and what are the implications of unpaid, unwaived overpayments for future use of benefits?❑ What proportion of families apply for and how many receive child support payments?❑ What proportion of families apply for and how many receive other welfare benefits over time?
<u>Caregiving/custody</u>
<ul style="list-style-type: none">❑ Are kin foster parents receiving support through the foster care system when SSI is ceased?❑ What options are available for families whose children have interrupted school days or absences imposed by their disability?❑ How do foster care payments for kin and non-kinship foster care compare to SSI payments? How do payments that kin caretakers are receiving compare to what they could receive within their state?

Because the case studies were designed to explore the types of effects experienced by families and agencies, and to inform the quantitative analyses, a number of important policy impact questions will require other data. For example, we purposely selected sites with high numbers of affected children. While we did visit one site with a significant rural population and interviewed families in rural locations, most of the interviews were conducted in large urban areas. It would be important to know how families in low density, rural communities are affected, and also how the policy effects differ for families in large urban areas that have lower volume and proportion of child SSI beneficiaries.

Finally, we do not know how the families who did not respond differed from those who did respond in terms of important outcomes such as the experience with the redetermination process and the impact of language or other barriers; changes in living arrangements or child entry into foster care; changes in family income and labor force participation; and so on. The case studies were intended to raise targeted questions about these possible effects rather than to assess national impact. Some of these issues will be explored further in the quantitative components of the evaluation.

8.4 CONCLUSIONS

The qualitative findings show that families were affected not only by the SSI changes but also by changes to cash assistance eligibility following welfare reform. About two-thirds of families reported that total household income had declined relative to the pre-welfare reform period. One-fourth reported that total household income had increased. Nearly half of the non-elderly and non-disabled parents had increased their working hours by the second interview in 1999. By 1999, equal proportions of interviewed families had increased their use of public assistance or reduced their use of public assistance.

The children in families we interviewed were not found to be participants in any specific federal or state program such as developmental services programs or the Title V program. Affected children in the families we interviewed had quite different impairments and related needs. A common theme echoed by families as well as administrators was the need for linking children with case management and with preventive services.

Interviews with Medicaid administrators and from families generally corresponded with respect to the policy impact on Medicaid eligibility and participation. For children under age 18, systematic losses of Medicaid eligibility were not expected by agency administrators. In the families we interviewed, those children under 18 who had lost Medicaid for any period of time had generally experienced an intermittent loss with coverage later restored. For the small number of children under 18 who remained unenrolled in Medicaid by 1999, changes in household income made it difficult to know whether the children were financially eligible or not. Children age 18 and above experienced eligibility problems. Medicaid administrators identified those over age 18 as a

group whose eligibility could be adversely affected by SSI loss. The majority of those over age 18 who lost Medicaid were uninsured at the 1998 and 1999 interviews. Few reported having impairments that were leading to unmet health needs given lack of health insurance.

Finally, few families stated that the SSI loss had adversely affected the child's health status. A large number of families identified access to quality medical care or mental health care as a more significant problem. Families did not perceive these access problems as related to loss of SSI or even loss of Medicaid. Instead, parents voiced concerns about their inability to find a provider with training they considered appropriate for their child's needs. Both families and a number of agency administrators reported that preventive or supportive services in mental health and child welfare were not always adequate to meet the need in their communities. Agency administrators often noted that children such as those affected by the new SSI disability definition may not be identified until those families who are unable to cope reach a crisis stage. Overall, our findings suggest that income support to kin caregivers, direction of families to qualified providers, and ways of directing families to pre-crisis support services were primary needs of families losing SSI income.

Findings from regional and local SSA offices and from state DDS offices portrayed a complex implementation process that continued to evolve for a long period after the initial regulations were issued. A well-defined and fair determination process for children appeared to be the result.

APPENDIX OVERVIEW AND CHRONOLOGY OF REDETERMINATION PROCESS

This appendix describes the SSI disability determination process resulting from the 1996 welfare reform changes and the subsequent review procedures put in place following the Balanced Budget Act of 1997 and the Commissioner's Top-to-Bottom review in Fall 1997.

A.1 REDETERMINATION PROCESS FOLLOWING PRWORA

SSA began with a total redetermination workload of 288,000 childhood cases based on the universe of children receiving SSI as of August 1996 as identified from the Universe File. Of that group, 23,658 cases were continued prior to notices being sent because a paper review of their files determined that they met the eligibility criteria under the new law. The remaining 264,342 cases received notices by December 1996 that their benefits may be ceased following a redetermination of their disability status. Benefits for an additional 4,666 cases that were still under review when notices were sent were subsequently continued because they were found to meet the new criteria. This left a total of 259,676 cases to be redetermined.

The redetermination process begins with a review at the initial level. For cases that are ceased at the initial level, the process continues through a 60 day appeal period and upon appeal the case moves to a review at the reconsideration level. Ceased cases at the reconsideration level can be appealed next to an administrative law judge (ALJ). The third level of administrative appeal is the Appeal Council, and a final appeal is available through a civil action in federal district court.

Initial Level. At any point in time in the redetermination process, the 259,676 childhood disability cases subject to redetermination can be classified into the following outcomes at the initial level: (1) redetermined at the initial level and continued, (2) redetermined at the initial level and ceased, (3) ceased for non-disability reasons.

60-Day Appeal Period. For those cases that are ceased at the initial level, the child and/or the child's representative may appeal the decision within 60 days. The child's benefits may continue during the appeal period if requested within 10 days of the notice of cessation. The child or the child's representative is told that payments received following an appealed cessation decision that is ultimately affirmed should be repaid to SSA, but that this requirement may be waived following recipient request and SSA's evaluation of the recipient's circumstances. Of those cases that appeal, some elect to continue benefits during appeal and others do not.

Reconsideration Level. For those cases that appeal after the initial level, the cases are redetermined at the reconsideration level. This review is composed of a case file review, and if necessary this is followed by a face-to-face hearing before a Disability

Hearing Officer (DHO). These cases can be (1) redetermined at the reconsideration level and continued, or (2) redetermined at the reconsideration level and ceased.

Subsequent Appeals and Reconsiderations. For cases ceased at the reconsideration level, the child and the child's representative may pursue three more levels of appeals, with a disability determination decision following each appeal. The second appeal leads to a hearing before an ALJ, the third appeal is before the Appeals Council, and the final appeal requires filing a civil action in federal district court. Few of these higher-level appeals and reviews have been conducted to date for the cohort of children affected by the welfare reform legislation.

Reapplications After Cessation. Cases that are ceased as a result of the redetermination process may reapply for SSI benefits at a later date. In some cases, reapplicants will qualify because of a change in their disability status.

Process for Age-18 Cases. The redetermination process for the age-18 cases mirrors the process for the childhood cases, with the exception that no cases were screened out initially because they all are subject to redetermination regardless of diagnosis. The evaluation criteria differ from those used for childhood cases.

A.2 POLICY CHANGES FOLLOWING THE BALANCED BUDGET ACT OF 1997 AND THE COMMISSIONER'S 1997 TOP-TO-BOTTOM REVIEW

The 1997 Balanced Budget Act (BBA) modified several aspects of the redetermination process for childhood cases. First, the BBA provided for the "grandfathering" of Medicaid eligibility for children subject to redetermination who lost SSI benefits. Other changes included extending the date by which SSA was to complete the disability redeterminations because of the PRWORA from August of 1997 to February of 1998 or when practical thereafter. In addition, the law provided that SSA may perform an age-18 redetermination within the one-year period following the child's 18th birthday or in lieu of a continuing disability review if SSA determines the case is subject to redetermination. The BBA also included a provision that allows SSA to determine that a continuing disability review (CDR) is not necessary at age one if the child has an impairment that is not expected to improve by that age.

SSA Commissioner Apfel initiated a "Top-to-Bottom" review of the implementation of the childhood disability redetermination process in Fall 1997. The report of the Commissioner in December 1997 identified concerns about the treatment of cases involving a diagnosis of mental retardation (MR), the accuracy of case processing across states and by impairment, and the exercising of appeal rights and benefit continuation requests when child cases were ceased. Several case review policies and procedures were put into place pursuant to the Commissioner's Report.

Reappeals and Benefit Continuation Renotification The appeals and benefit continuation processes timeframes were extended. Specifically, children whose eligibility was ceased as a result of the redetermination, and who did not appeal, were to be given a

new 60-day period to appeal the decision, and a 10-day period to request benefit continuation. The Reappeals and Benefit Continuation notices (also known as "good news" letters) included simplified language to ensure that parents understood their options. SSA sent both Spanish and English language notices to individuals who had not appealed initial determinations or did not request benefit continuation during appeal. These notices also included a list of toll-free telephone numbers so that individuals could obtain free legal advice. As of November 1, 1997, SSA had reviewed 235,000 cases resulting in approximately 141,300 cessation decisions, a 60 percent cessation rate. As of that date, 67,946 appeals requesting reconsideration had been initiated. Approximately 50 percent of cessation cases had not appealed and were eligible for re-opening.

Review of Mental Retardation (MR) Cases. SSA was to review all cases ceased after redetermination that had a MR primary diagnosis code, and all initial applications with that code that were adjudicated after August 19, 1996 and denied. MR cessation cases that involved an IQ less than 75 would automatically be reopened; cases where IQ was above 75 would first be reviewed and then reopened if deficiencies were found. This was estimated to affect 40,000 cases.

Review of "Failure to Cooperate" Cases. All redetermination cases where benefits were ceased based on a "failure to cooperate" were to be reviewed to ensure that the cooperation of child beneficiaries' families was fully sought and documented. These cases occurred when the child's parent or legal guardian did not respond to the initial redetermination notice or failed to cooperate with SSA's redetermination process. Cessations based on failure to cooperate made up less than 5 percent of all cases, ranging from less than 1 percent to 9.5 percent of cases across states.

Quality Review Provisions. All Disability Determination Service (DDS) offices were to undertake a review of a portion of their redetermination cessations, beyond those described above. SSA would determine the types of cases to be reviewed by each office, selecting cases with the highest likelihood of error based on quality assurance data.

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